Cognitive Aspects of Childhood Asthma

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Declaration

I, Mark Stein, declare that this thesis is my own work except where collaboration in writing, and incorporated comments of others has been indicated (see acknowledgements). I have been responsible for preparing the first draft of each piece of written work, for developing the original design of each study, and for conducting the research, and analysing the results. I confirm that that the thesis has not been submitted for a degree at another University.

Summary

Research was undertaken to improve our knowledge about children's awareness of respiratory sensations, beliefs about asthma of children with asthma and their parents, the nature and extent of childhood asthma sufferers' psychological difficulties, and parents' and children's reasons for achieving good control of asthma. Recognition and accurate reporting of respiratory sensations have implications for asthma management. Illness beliefs explain differences in adaptation to chronic disease. Childhood asthma is situated within a family context. Asthma severity and the source of information may explain differences in reports of children's psychological well-being. Low adherence with treatment recommendations has been reported, and chronic disease can influence quality of life.

Participants were recruited from a hospital asthma database, primary care patient lists, and through state primary schools. The interviews involved physically healthy children, children with asthma, and the parents of children with asthma. Qualitative and quantitative methods involved the use of storyboards, semi-structured interviews, and questionnaires.

The main arguments are that, (i) social interaction, in the context of childhood asthma, is a determinant of children's sophisticated descriptions of respiratory sensations, (ii) children's understanding of the different aspects of asthma is determined by their personal salience, and the necessity of acquiring strategies to resolve asthma-related difficulties, (iii) concordance in the beliefs of parents and their child about the child's asthma is associated with less conflict about the child's disease and disease-related situations, and the quality of family life mediates the relationship between belief concordance and the child's psychological well-being, and (iv) participants' reasons for achieving good control of asthma reflect the aspects of their lives that are most affected by asthma.

It was concluded that the personal salience of different aspects of childhood asthma may encourage an awareness of symptoms, prompt discussion of internal states, foster concordance in beliefs, and motivate adherence with treatment recommendations.

Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
HIV	Human Immunodeficiency Virus
IDDM	Insulin-dependent diabetes mellitus
IPQ	Illness Perception Questionnaire
IPQ-C	Child version of the modified, asthma-specific Illness Perception Questionnaire
IPQ-P	Parent version of the modified asthma-specific Illness Perception Questionnaire
ISAAC	The International Study of Asthma and Allergies in Childhood
MHLC	Multidimensional Health Locus of Control Scale
SD	Standard deviation
SDQ	Strengths and Difficulties Questionnaire
SDQ (P4-16)	Extended version of the Strengths and Difficulties Questionnaire for parents of 4-16-year-old children
SDQ (S11-16)	Extended version of the Strengths and Difficulties Questionnaire for 11-16-year-old children

Introduction

Asthma is perhaps the most common chronic disease of childhood (Eiser, 1990a). Recent estimates suggest that 20% of primary school age children in the UK have asthma (ISAAC Steering Committee, 1998). It is an inflammatory disease (Scadding & O'Connor, 1998) that is characterised by wheeze, breathlessness, chest tightness, and cough (Ayres, 1999). Illness episodes are characterised by intermittence, variability in severity (between and within individuals) and reversibility (Moss, Fitzharris, Frater, Keeley & Fatz, 1996; Taitel, Allen & Creer, 1998). Although a genetic component to asthma has received support in the literature, physiological and environmental factors have also been implicated in its aetiology (Fritz & Wamboldt, 1998; Lane, 1996). An exacerbation of asthma may be triggered by a variety of factors, including dust, exercise, and viral tract infections (Gibson, Henry, Vimpani & Halliday, 1995; Lane, 1996; Morrison, 1998). Emotions and stress may also serve as triggers of an asthma episode (Kotses, 1998; Sandberg, Paton, Ahola, McCann, McGuiness, Hillary & Oja, 2000). The consequences of asthma may affect a patient's physical health, their psychological well-being, and their participation in education and social activities (Action Asthma, 1993; Celano & Geller, 1993; Donnelly, Donnelly & Thong, 1987; French, Christie & West, 1994; Graetz & Shute, 1995; Hilton, 1991; Hyland, 1998; Hyland, Kenyon, Taylor & Morice, 1993; Janson & Reed, 2000; Nocon & Booth, 1991; Osman, Russell, Friend, Legge & Douglas, 1993; Pradel, Hartzema & Bush, 2001; Snadden & Brown, 1992; Taitel et al., 1998; Wamboldt & Wamboldt, 1996; Yoos & McMullen, 1996). However, modern treatment and environmental strategies are in the main effective in achieving control of the disease, and allowing childhood asthma sufferers to live normal lives (Ryan, 1998).

The early diagnosis of asthma, and the prompt initiation of appropriate treatment is likely to be contingent on a child's accurate perception and reporting of their symptoms and/or parents' awareness of their child's respiratory distress. Similarly, a child's ability to detect and respond to changes in their respiratory system has implications for asthma management (Fritz, McQuaid, Spirito & Klein, 1996; Fritz & Wamboldt, 1998).

Experience of symptoms may represent a perceived health threat. It has been suggested that people are motivated to reduce their health-related risk, and act to reduce perceived threat in ways that are consistent with their beliefs about that threat (Leventhal, Nerenz & Steele, 1984). This self-regulatory model is based around three stages: (i) Representation, (ii) Coping, and (iii) Appraisal. The representation stage involves the representation of the perceived health threat and its associated affect. This has been suggested to determine in part the individual's subsequent coping behaviour. The appraisal stage evaluates the effectiveness of coping and may feedback into the representation and coping stages.

In recent health psychology literature, the representation of a perceived health threat has been conceptualised in terms of a patient's beliefs about different aspects of their illness experience (Petrie & Weinman, 1997). These include the symptoms that are associated with a disease, its cause, its duration, its consequences and its cure (Lau & Hartman, 1983; Leventhal, Benyamini, Brownlee, Diefenbach, Leventhal, Patrick-Miller & Robitaille, 1997).[1] It has been suggested that there may be prototypical beliefs about specific components of illness representation, for example, that diseases have a short duration (an acute Time-Line belief) (Meyer, Leventhal & Gutmann, 1985). For this reason, some illness experiences, for example, experience of asthma, may necessitate a modification of prototypical illness beliefs (Snadden & Brown, 1992).

Experience of asthma may also be associated with distress (Hyland et al., 1993; Snadden & Brown, 1992; Taitel et al., 1998). Although as a group, children with asthma do not generally differ from physically healthy children and normative data in terms of their psychosocial well-being (Bender & Klinnert, 1998), psychological disturbance may be a risk for children with severe asthma (Norrish, Tooley & Godfrey, 1977; Wamboldt, Fritz, Mansell, McQuaid & Klein, 1998).

Independently of psychological difficulties, the physical intrusiveness of asthma and aspects of its treatment may influence patients' quality of life (Eiser & Morse, 2001; Hutchinson, Hewison & Eccles, 1996; Juniper, 1998). Symptoms of asthma have

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[1] The cognitive developmental literature suggests a similar conceptualisation of illness experience and developmental differences in the representation of specific components of illness representation have been suggested (Rosenthal, Waters & Glaun, 1995; Schmidt & Weishaupt, 1990).

been linked with poor self-care (Sibbald, 1989). Low adherence with treatment recommendations has been reported in the literature (Deaton, 1985; Fritz & Wamboldt, 1998; Hilton, 1991). In contrast, perceptions of well-controlled asthma have been associated with fewer breathing difficulties, fewer and less serious exacerbations of asthma, less disruption to normal activities, and fewer emotional difficulties (Janson & Reed, 2000). Recent advances in health psychology have attempted to improve patients' motivation or volition with respect to engaging in health-related behaviour (Abraham, Sheeran & Johnston, 1998; Fuhrmann & Kuhl, 1998).

Outline of the Thesis

Between February 1998 and February 2002, four studies were undertaken to improve our knowledge about different aspects of childhood asthma. An initial exploratory piece of research was concerned with children's awareness of respiratory sensations and their knowledge about the respiratory system. The developmental literature concerning children's understanding of illness was reviewed to provide a background for this work and is introduced in chapter 1. The shift from research orientated towards the traditional Piagetian framework is described and alternative paradigms are discussed. These include domain specific perspectives and approaches that have emphasised the role of social interaction and experience. The discussion of illness conceptualisation from a health psychology perspective is continued in chapter 2.

Illness cognition is described in terms of illness prototypes, illness schemata, and Leventhal et al.'s (1984) self-regulatory model. The discussion proceeds to consider different components of the cognitive representation of illness i.e., symptoms, cause, duration, consequences and controllability, and how illness cognition may serve to determine illness behaviour and health outcome. The chapter concludes with a discussion of how cognitive representations of illness may be acquired and developed.

Different aspects of childhood asthma are discussed in chapter 3. These are reviewed in the context of illness representation components and the different factors that may influence patients' beliefs about asthma. The main thesis that concordance in beliefs of parents and their child about the child's asthma is associated with psychological well-being is introduced.

An overview of the empirical studies and methods is presented in chapter 4, with details of the instruments that were used.

Initial, exploratory research and a replication study are presented in chapter 5 and chapter 6 respectively. These studies consider how children acquire the language that they use to describe respiratory sensations. The main thesis is that social interaction, in the context of relevant experience, is a determinant of children's sophisticated descriptions of respiratory sensations.

The conceptualisation of illness from a health psychology perspective constituted the basis of the study reported in chapter 7. The first thesis is that children's understanding of the different aspects of asthma is determined by the salience of each aspect to their daily lives and the necessity of acquiring strategies to resolve specific, asthma-related difficulties. The second and main thesis is that concordance in the beliefs of the parents and their child about the child's asthma is associated with less conflict about the child's disease and disease-related situations, and that the quality of family life mediates the relationship between belief concordance and the child's psychological well-being. The third thesis is that the participants' reasons for achieving good control of asthma reflect the aspects of their lives that are most affected by asthma.

The study reported in chapter 8 extended the findings of the previous study's three analyses by including disease severity as an additional variable. A fourth analysis returned to the theme of respiratory sensations and aimed to test the thesis that disease severity, parental sensitivity to their child's internal state, and family discussion about asthma are associated with the quality of children's descriptions of respiratory sensations.

The main findings of the research are summarised and discussed in chapter 9. Particular attention is devoted to a discussion of the main limitation of the studies, a low response rate. The chapter concludes with suggestions for future research.

Chapter 1 Children's Understanding of Illness

1.1 Introduction

In considering the way in which children think about and organise their ideas about illness it is necessary to consider not only the nature of illness representations (see chapter 2), but also the influence of children's general cognitive developmental level, and the cognitive representation of illness within the context of a specific illness (chapter 3).

There now exists a considerable literature on children's cognitive development and understanding of various phenomena including conservation (Donaldson, 1978), scientific and mathematical concepts (Nunes, 1995) and biological phenomena such as health and illness (Siegal & Peterson, 1999). What is common to each of these approaches to the study of children's cognitive development is an attempt to retain a focus on the developmental aim of not only describing what develops and when, but also how it develops (Bee, 1995).

Traditional Piagetian explanations of children's understanding of various phenomena such as health and illness were closely allied to Piaget's four-stage theory of cognitive development (Burbach & Peterson, 1986; Eiser, 1989; Rushforth, 1999). However, some authors have criticised Piagetian explanations for forcing data into a cognitive framework e.g., Eiser (1989).

In addition, social constructivists such as Vygotsky considered that a Piagetian approach underplayed the role of social interaction as a determinant of children's cognitive development, and suggested that cognitive development proceeds from the internalisation of social interactions (Das Gupta & Richardson, 1995). In this respect, Nelson's (1986) 'script' theory of cognitive development exemplifies recent attempts to integrate findings from previous Piagetian-style research with those derived from more recent work that was sensitive to real world validity and the role of social context in supporting cognitive development.

Further refinements of the theories of children's cognitive development included a shift in the developmental literature from explanations based on general cognitive development (e.g., Bibace & Walsh 1980; 1981) to a consideration of modularity and domain specificity (e.g., Keil, 1994; Siegal & Peterson, 1999) (for reviews of the literature on children's understanding of illness, see Burbach & Peterson, 1986; Eiser, 1989; Rushforth, 1999; Yoos, 1994). That is to say, the development of specific innate neural systems (modules) that exist to process different types of information input, for example, language information, and that lead to the development of a set of representations that constitute the basis of the knowledge base and the cognitive processes associated with it (Das Gupta & Richardson, 1995).

With this in mind, there seem to be several threads to the emerging discussion about children's cognitive development. These include the traditional Piagetian, the functionalist, and the social constructivist approaches. In this chapter, theories and research concerning children's understanding of illness will be presented and discussed. The aim is to present an overview of the theories as to how children acquire and develop cognitive representations of illness, and to describe some of the research that has been cited in support of cognitive-developmental, domain-specific, and social constructivist accounts of this development.

1.2 The Piagetian Cognitive-Developmental Perspective

Piagetian theories of children's cognitive development emphasise the role of the child as an active constructor of knowledge (Das Gupta, 1994). Through interaction with the environment and the internalisation of actions the child is suggested to develop cognitive structures that represent the external environment and relations within it (Donaldson, 1978). Piaget suggested that children's cognitive development could be characterised as a progression through discrete stages, each stage building upon and being qualitatively different from the stage that preceded it (Donaldson, 1978). The four stages proposed by Piaget have been termed (i) the sensorimotor, (ii) the preoperational, (iii) the concrete operational, and (iv) the formal operational stages of cognitive development (Das Gupta, 1994). According to Piaget each stage is characterised by a qualitatively different mode of thinking (Eiser, 1989). These proposed differences in the nature of children's thinking have for the most part been referred to when attempting to explain children's understanding of different phenomena, including health e.g., Goldman, Whitney-Saltiel, Granger and Rodin (1991), illness e.g., Bibace and Walsh (1980; 1981), and bodily functioning e.g., Crider (1981). These explanations centre round the idea that children's cognitive developmental level represents a general level of development that constrains understanding across all domains (Hergenrather & Rabinowitz, 1991).

1.3 Cognitive Development and Cognitive Representations of Illness

Bibace and Walsh (1981) referred to how children with illness can experience a range of emotion in response to an illness, and acknowledged that while distressing feelings were a laudable focus of therapeutic endeavour, underlying those feelings were individual cognitive representations and understandings of illness. The main emphasis of their discussion was that although there is considerable variability in children's concepts of illness and illness causality, of equal significance is the extent to which there is a developmental pattern of illness conceptualisation. In particular, it was emphasised that children's concepts of illness at different ages were qualitatively different, in both general levels of explanation of illness and in the specific content of those explanations.

In their study of children's explanations of illness, and in particular illness causality, Bibace and Walsh (1981) suggested three general categories of explanation corresponding to (i) the preoperational, (ii) the concrete operational, and (iii) the formal operational stages of cognitive development. Each general category was suggested to contain two subtypes of explanation: phenomenism and contagion at the preoperative level, contamination and internalisation at the concrete operational level, and physiological and psychophysiological at the formal operational level. This sequence in the kind of explanations offered by children was suggested to parallel a shift in reasoning from concrete, perception-bound, magical-thinking to an increasing differentiation of the self from others and of the internal world from the external world, to logical and abstract reasoning with the greatest amount of differentiation of the internal and external world. Bibace and Walsh (1981) interviewed twenty-four 4-year-olds, twenty-four 7-year-olds and twenty-four 11-year-olds about a range of illnesses, and reported an interpretable pattern to the levels of explanations of illness associated with each of the three age groups. This pattern was reported to be consistent with their predictions based on age as an indicator of cognitive-developmental level.

Research in support of Bibace and Walsh's (1981) claim for a developmental progression in the nature of children's illness concepts has also used age as an indicator of cognitive-developmental level, and has examined differences between the illness concepts of younger and older children e.g., Campbell (1975), Perrin and Gerrity (1981). In comparison with younger children, the reports of older children reportedly had greater conceptual sophistication (Campbell, 1975) and organisation (Perrin & Gerrity, 1981), more frequent reference to internal body cues (Neuhauser, Amsterdam, Hines & Steward, 1978), and greater specificity of description (Campbell, 1975).

Assuming that age is a valid indicator of cognitive developmental level, the implication of these findings is that children's explanations of illness are consistent with their cognitive developmental level. A child at the preoperational stage of development, for example, may talk about asthma caused by a curse whereas a child at the concrete operational stage may talk about asthma caused by breathing cold air into the lungs. A child at the formal operational stage of development may talk about asthma caused by inflammation in the lungs, exacerbated by emotional conflict. It is worth noting that the extent to which illness experience interacts with developmental level is only recently beginning to be investigated e.g., Paterson, Moss-Morris and Butler (1999) (see page 19).

Although intuitively it might be expected that illness experience would make accurate and sophisticated explanations of illness more likely, it may be that emotional responses to illness obstruct the cognitive developmental process with respect to illness concepts (Thompson & Gustafson, 1996). However, Eiser (1991) suggested that, rather than influencing children's cognitive abilities, experience of illness has implications for their emotional development. Bibace and Walsh (1981) referred to ambiguity in the literature as to whether illness experience facilitates or impedes the development of children's illness explanations. If affective states associated with illness experience promote information-seeking and understanding, illness experience may lead to more accurate and sophisticated explanations of illness. If however, affective states associated with illness experience are sufficiently distressing to inhibit information-seeking or lead to denial, experience of illness may lead to regression or inhibition of the child's illness concepts. The crucial determinant of whether illness experience and its associated affective states facilitate or impede the development of illness explanations is likely to be the way in which individuals represent (interpret) and self-regulate (cope with) their illness experience.

1.4 Early Research into the Cognitive Representation of Illness

The work of Campbell (1975) is an example of the early psychological research that focused on how children and their parents represent illness and as such is worthy of more detailed consideration. This research provided an initial insight into the way that children and their parents conceptualised and made decisions about illness, and suggested how children may develop illness concepts. However, this research was a considerable distance from that concerned with illness cognition and the implications of illness representation components of specific illnesses for health and health-related behaviour e.g., Petrie and Weinman (1997) (see chapter 2).

Campbell (1975) interviewed two hundred and sixty-four 6-12-year-old children and their mothers to determine the extent of consensus in their concepts of illness, and developmental changes in the children's illness concepts. The children were all short-term paediatric in-patients. Although no information was provided about their individual diagnoses, health and illness were likely to be a particular concern for them and their mothers.[1]

In response to questions about how respondents identified illness, Campbell's (1975) findings suggested a concern with the consequences of illness. For example, "... if I have something that hurts ..." (Campbell, 1975, p. 93) or "... I can't get up and feed the children ... " (Campbell, 1975, p. 93). Eleven principal

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[1] In the context of chronic illness, patients admitted for acute treatment of a single health episode (and their relatives) may differ from patients admitted for inpatient management of chronic health episodes (and their relatives), in ways that are particularly relevant to an investigation of concepts of illness.

themes defining illness were identified from the responses of 24 mothers and 24 children, and on the basis of these themes interview responses were coded. Of the eleven themes, nine were concerned with Identity (signs and symptoms) or Consequences. These included (i) non-localised, non-specific feelings, (ii) non-localised but specific feelings, (iii) specific and localised feelings, (iv) visible external signs, (v) objective signs that were not visible, (vi) mood, (vii) sick role behaviour, (viii) alterations in conventional role, and (ix) behaviour of others. The remaining themes related to disease Identity in terms of specific disease concepts or diagnoses, and a qualification of the illness concept to exclude illnesses such as having a cold.

The predominance of Identity and Consequences components among these themes emphasises the functional nature of illness representations and suggests a link with decision-making processes, an acute model of illness (see chapter 2), and the social context of illness. Illness representation components of Time-line (illness duration), Cause and Cure/Control were not referred to in the examples that Campbell provided, suggesting that representations of illness in general are not necessarily the same as representations of specific illnesses. In this respect however, it should be noted that respondents were not asked to say what they thought illness was but to say what was different about being well and being ill.[2] [3]

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[2] Kalish (1999) referred to illness as a higher order concept in a kind-hierarchy concept of illness. It was suggested that specific illnesses or types of illness were represented within the kind-hierarchy as natural kinds. Kalish also suggested that for children, contagious illnesses might represent an illness natural kind as well as an early prototype of illness. Experience and education were suggested as determinants of both the differentiation of contagious illness into concepts about specific contagious illnesses, and children's development of concepts about illnesses other than those that are contagious. Kalish's levels of generality to study concepts of illness therefore include illness (higher order), infectious diseases (intermediate level distinguishing between illnesses with different causal processes) and specific types of diseases (natural kinds). It was suggested that children may not appreciate the distinction between specific diseases and that children's thinking about illness may be organised in such a way as to allow them to distinguish between diseases with different causal processes.

Campbell's (1975) results suggested a consensus amongst the children as to what constitutes illness, or rather a consensus as to how children talked about illness. Non-localised and non-specific descriptors were reported most often, with considerably fewer reports of psychosocial definitions, reference to specific diagnoses, and qualification of what does not constitute illness. Insofar as developmental changes were concerned, Campbell reported an overall convergence of children's illness concepts (talk) with the illness concepts (talk) of their mothers. However, in a discussion of the likely transmission of illness concepts (language of illness) from mother to child, Campbell reported no evidence of a connection between the descriptors of any given child and their mother. In comparison with younger children, older children were significantly more likely to refer to specific diseases, alterations in conventional role behaviour, and to say what illness was not. The younger children were significantly more likely to define illness in terms of non-specific and non-localised sensations. Whereas, in general, the children primarily tended to focus on both non-specific and non-localised sensations, and localised and specific sensations, mothers tended to emphasise specific disease concepts or diagnoses, objective signs detectable by means other than visual examination, and the psychosocial dimensions of illness. These differences were attributed to the greater conceptual sophistication of the mothers. However, it was emphasised that the children also demonstrated the full range of conceptual sophistication in their definitions of illness.

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[3] The technique of focusing on differences between health and illness rather than on absolute indicators has been employed therapeutically as well as in research. For example, Berg and Miller (1992) reported on the effectiveness of 'miracle questions'. These hypothesise a scenario in which problems mysteriously vanish. Patients are then asked to describe how they would know that their problem had disappeared. Their responses would then be used to identify treatment goals. Anecdotally, this technique has received initial support in the treatment of asthma; children were asked to say how their lives would be different if they did not have asthma. The children's responses constituted the goals for their treatment. It may be hypothesised that the children's responses were also likely to indicate the particular areas of children's lives where asthma had an impact, and the extent to which different dimensions of quality of life were salient for different children.

The possible sources of variation in conceptual sophistication described by Campbell (1975) included general cognitive development (there was a significant correlation between age and conceptual sophistication), and health history and experience of illness, particularly in relation to the health of the child's parents. Campbell suggested that it was perhaps because of cognitive development that, in comparison with the younger children, the older children were more likely to make sense of their illness experiences, and to develop more sophisticated concepts (language) of illness. Campbell emphasised a developmental progression from a concern with feeling states to a more precise focus on specific illnesses, as well as an expansion of definitions to include psychosocial aspects of illness. He emphasised that the data did not support the view that a child's acquisition of illness concepts (ways to describe illness) followed directly from maternal tuition. Instead, it was suggested that mothers' illness concepts might only impinge upon the illness concepts of their children insofar as the mothers' concepts of illness relate to the illness experiences of the child.

Millstein, Adler and Irwin (1981) also investigated developmental trends in health beliefs, comparing the illness definitions of 11-15-year-olds with those obtained from children and adults. Millstein et al. acknowledged that a cognitive-developmental framework, as described by Bibace and Walsh (1981), clearly demonstrated the parallel development of illness concepts and cognitive development. However, they argued that during adolescence there is considerable expansion of children's social environment. For this reason, it was suggested that it is necessary to consider the social dimensions of illness beliefs as well as the cognitive dimensions.[4] Although Campbell's (1975) sample included 12-year-olds, Millstein et al. observed that the responses of the young adolescents were

[4] Millstein et al.'s (1981) discussion made little reference to the social dimensions of illness beliefs that they had explicitly referred to in their introduction.

combined with the responses of the younger children in an adult-child comparison and were not considered independently of the responses of the younger children. It was suggested that because adolescents are able to think in more abstract ways than younger children, and because of greater autonomy, are likely to participate to a greater extent in the self-management of their health and illness, the illness beliefs of the adolescents were likely to differ from those of the younger children.

Millstein et al. (1981) adopted a similar procedure to Campbell (1975). The adolescents were individually interviewed and were given the scenario that on one day they know they are well and on another day they know they are sick. They were then asked to describe the difference. Campbell's (1975) categorisation system was used to code their responses.

In terms of thematic content, Millstein et al. (1981) reported that 90.8% of the responses could be coded as representative of somatic feeling states, although no data were reported on the proportion of adolescents' responses in each of the three somatic symptom categories: (i) non-localised and non-specific sensations, (ii) non-localised and specific sensations, and (iii) localised and specific sensations. Other proportions were similar to those reported by Campbell (1975). In terms of conceptual sophistication, Campbell's adult themes were relatively under-represented in the responses of the adolescents, whose thematic profiles were more similar to those of Campbell's child sample. The exception to this was a trend for the adolescents to report definitions of illness as an inability to participate in their usual activities (28.6% of adolescents; Millstein et al., 1981), a theme represented in the reports of 42.6% of adults and 10.7% of children (Campbell, 1975).

In terms of children's knowledge and representations of internal body parts and physiological systems, several researchers have considered these matters from a cognitive-developmental perspective e.g., Gellert (1962), Nagy (1953), Porter (1974), Schilder and Wechsler (1935). These authors suggest that with development, children's knowledge of specific body parts and physiological systems becomes increasingly differentiated, while representations of distinct physiological systems become increasingly integrated (Crider, 1981). Insofar as breathing and the respiratory system are concerned, little specific information about children's understanding has emerged. Gellert (1962) described how, with increasing age, there is a greater tendency for children to identify and locate components of the respiratory system correctly, and accurately describe lung function and respiration. The age range of Gellert's participants was 4 years 9 months to 16 years 11 months. Very few of the younger children in this study were either willing or able to express what might happen to air after it has been breathed in, or to discuss how breathing and respiration are integrated with other physiological systems in a complete biological system.

More recently, Clarke and Newell (1997) have reported similar findings, although they also considered the role of experience in determining children's knowledge of internal body parts. They reported significant associations between children's knowledge about internal body parts and age, but no significant difference between the knowledge of children with asthma and the knowledge of physically healthy children. Similar findings were reported concerning children's ability to talk about the lungs. Perrin, Sayer and Willett (1991) also reported that age was a predictor of children's understanding of body functioning. However, with respect to children's experience of illness, although children's understanding of body functioning was independent of their experience of illness, children's general reasoning skills were a significant predictor of their understanding of body functioning. When children's general reasoning skills were taken into account, in comparison with physically healthy children, children with a chronic illness (either an illness that involved an orthopaedic condition or a seizure disorder) had a similar or somewhat better understanding of body functioning. Perrin et al. speculated that, through questions and discussion about specific, personally salient aspects of body functioning, children with a chronic illness might develop a better understanding of body functioning. The study reported in chapter 5 considers the extent to which relevant experience and age are associated with children's knowledge of the respiratory system.

Developmental studies, such as those referred to above, have been criticised for their poor description of samples, instruments and procedures, a disregard of observer expectancies and bias, a lack of methodological rigour in controlling for potential confounding variables, and shortcomings concerning reports of reliability and validity (Burbach & Peterson, 1986). In addition to these methodological criticisms, Eiser (1989) claimed that the cognitive developmental perspective could be criticised on theoretical grounds. Advocates of the functionalist perspective (e.g., Paterson et al., 1999) claimed that the cognitive-developmental perspective does not take into account the role of personal illness experience and socio-cultural factors. In this context, it is worth considering the value of Carey's (1985) theory of conceptual change and Nelson's (1986) 'script' theory.

1.5 The Development of Illness Cognition: A Domain-Specific Perspective

Carey (1985) suggested that children develop a theory of biology from a naive psychology. That is, children's explanations of biological phenomena were suggested to develop from explanations conceptualised in terms of intentions and desires to explanations conceptualised in terms of biology. In this model, similarity with human beings was a major determinant of perceived biological status. On the basis of her findings, Carey suggested that children acquire what could be considered a theory of biology at around the age of ten years. Keil

(1992) however, suggested that children are aware of the distinction between biological kinds and non-biological kinds at a much earlier age.[5] He suggested that a theory of biology either develops from intuitive general domains such as a naive psychology (becoming a specific biological theory through education or experience) or from a specific predisposition to construe biological phenomena as biological phenomena from the earliest stages of development.[6] It was suggested that young children's ability to distinguish non-biological kinds and biological kinds ran counter to Carey's (1985) claim that children make inferences about biological status, as well as construe biological explanations, on the basis of perceived similarity with human beings.

Inagaki and Hatano (1999) also questioned the validity of any claim that children explain biological phenomena in terms of psychological modes of construal. They suggested that even preschool children differentiate between mental and somatic phenomena. Specifically, it was suggested that while the former may be explained in terms of a naive psychology, the latter were often explained in terms of vitalism.[7] The achievement of vitalism has been suggested as the key accomplishment of conceptual change in children's developing theory of biology,

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[5] Hatano and Inagaki (1994) concluded that children as young as six years of age possess a knowledge of the distinction between living and non-living things, employ a constrained personification (make analogies to human experience) to generate predictions about outcome, and explain biological phenomena in terms of non-intentional causality i.e., vitalistic causality or mechanical causality. They claimed that these three components of children's understanding represented a naive biology that could be differentiated from a naive psychology.

[6] Hatano and Inagaki (1994) suggested an evolutionary-adaptive component to children's understanding of biological phenomena such as bodily functions, health and illness. This understanding was suggested to be a prototypical and adaptive understanding that, through specific experience, undergoes a conceptual shift, to become an understanding of biology that is characterised by category-based inferences for health and illness phenomena.

[7] Vitalistic explanations attribute biological phenomena to a vital power, or energy, or to an internal organ with agency that is essential for maintaining and enhancing life.

that allows for the development of a core concept of 'life' (Slaughter, Jaakkola & Carey, 1999). Children's achievement of the life concept allows for the differentiation of early non-biological concepts that, for example, define living as behaviour, and the integration of plants and animals into a single category of 'living thing' (Carey, 1985; Slaughter et al., 1999). The suggestion is that children with the concept of life, or 'life-theorisers', are able to use the life concept to make sense of other experiential and somatic phenomena, and have been reported to demonstrate coherence among other related biological concepts such as knowledge of bodily functioning (Slaughter et al., 1999). Specifically, it was reported that among children who have yet to develop the life concept, a linear relationship exists between the accumulation of biological knowledge and knowledge about specific biological concepts such as death. Eventually this mutually supporting system of knowledge reaches a threshold and leads to the development of the life concept. At this point no correlation exists between biological knowledge and knowledge about specific biological concepts. Rather, it was suggested that after children have developed a life concept, the accumulation of further biological information simply adds detail to their existing biological theory. Slaughter et al. (1999) concluded that the biological concepts of life, death and bodily functioning develop coherently and this coherent development of specific biological concepts supports and provides a context for the development of other related concepts.

Au, Romo and DeWitt (1999) were also concerned with how children's biological theories develop. They maintained that although children's intuitive biological theories undoubtedly include an ontological distinction between biological kinds and non-biological kinds, representations of input-output associations (understanding that biological causal mechanisms mediate biological events), and cognitive engagement with a variety of biological phenomena, they are unlikely to emerge from experience alone and need to be explicitly taught. Au et al.

emphasised the distinction between knowledge of biological input-output associations and knowledge of biological mechanisms. The former was suggested to be a non-generative form of knowledge that develops from learning biological facts. The latter, generative form of knowledge was deemed necessary for any claim that children have an autonomous foundational theory in the domain of biology. That is to say, for children to be able to make accurate inferences about novel biological phenomena they would need to develop a knowledge and understanding of biological causal mechanisms through learning and education. In support of this position, Au et al. reported that children younger than 13 years of age were unlikely to spontaneously refer to biological explanations of biological phenomena, but that children as young as 8 years of age were quite capable of learning about biological causal mechanisms; in comparison with a control group of children who explained contagion and food contamination in terms of observable events, behaviour and mechanical processes, children taught an experimental curriculum about biological causal mechanisms were more likely to refer to biological causal mechanisms. Similarly, in comparison with a control group of children taught an existing AIDS curriculum, children taught about the biological mechanisms of AIDS were more likely to reach accurate conclusions about the risk of novel situations (Au et al., 1999). This distinction between knowledge of associations and knowledge of biological mechanisms is consistent with the work of Rosenthal et al. (1995), who distinguished between knowledge and understanding about HIV/AIDS.

Rosenthal et al. (1995) reported developmental differences in understanding of HIV/AIDS among pre-adolescents and adolescents. In the present context, perhaps the most noteworthy aspect of this research was the idea of comparing two measures of understanding. The first measure was a semi-structured interview with open-ended questions that assessed reasoning about the causes and prevention of HIV/AIDS. Four dimensions of assessment were concerned with causality and two with prevention. Participant responses were coded according to three levels of conceptual sophistication. The second measure was a 12-item questionnaire that used a true/false format. There were nine questions about the cause of HIV and three questions about its prevention.

Rosenthal et al. reported high levels of knowledge about HIV/AIDS based on questionnaire assessment. However, findings from the cognitive reasoning interview assessment suggested that, for the younger groups of children, levels of knowledge, as measured by the questionnaire, were higher than those assessed by interview. Rosenthal et al. concluded that knowledge of facts should be distinguished from understanding, and that with age there are improvements in an individual's ability to make connections between different facts, to develop concepts, and to attend to underlying principles rather than surface features.[8] While understanding may serve as a proxy for factual knowledge, Rosenthal et al.'s (1995) findings suggest that factual knowledge may not always serve as a proxy for understanding.

What remains to be considered is the extent to which increased understanding in one specific domain, for example, health and illness, is paralleled in other domains. Although a general level of organisation may determine children's cognitive representations within a domain (Carey, 1985), for example, health,

[8] It is also likely, that the extent to which conceptual change allows for a better understanding of illness causality and prevention, is a determinant of engagement in health behaviour, and in particular, engagement in preventative health behaviour (Rosenthal et al., 1995). In comparison with health education programmes with no self-mastery component, intervention strategies that assist children to develop self-mastery skills concerning asthma and its treatment are more effective in improving adherence with treatment and health outcome (Eiser, 1990b). This finding may be explained in part through an increased opportunity for children to cognitively engage with their illness concepts. This leads to a conceptual shift concerning the causes of asthma and its prevention. In terms of knowledge and understanding, it could be speculated that, whereas previously children with asthma knew they should take inhalers to prevent asthma, they now understand why they should take inhalers to prevent asthma. The conceptual shift provides a more accurate understanding of the rationale for the treatment of asthma, and that understanding may facilitate children's engagement with preventative treatment.

individual experience may have implications for children's levels of reasoning and cognitive representation in specific domain areas, for example, their cognitive representations of asthma. Experience of chronic intermittent asthma, for example, is likely to widen the range of inferences that can be made concerning the Time-Line (duration) of a disease.[9]

Goldman et al. (1991) examined the extent to which the quality of children's illness representations generalised to other dimensions of health. Although Goldman et al. reported an overall consistency in levels of understanding and explanation of different aspects of health, illness, nutrition and preventative medical examinations, they also identified a group of children who demonstrated greater variation in their levels of understanding than a group of stable responders. Analysis of the data indicated that this variance was attributable to differences in the children's knowledge of nutrition. The children with a greater variability in their explanations tended to have a greater knowledge of nutrition than would have been predicted on the basis of their descriptions of illness causality or knowledge about preventative medical examinations. Goldman et al. suggested that such décalage supported the role of factors other than cognitive maturation in promoting children's understanding of nutrition.

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[9] In this respect, although script theory (Nelson, 1986) relates to familiar time-limited events, it is possible to consider an extension of its application. Scripts are suggested to be spatially-temporally organised, cognitive representations of events, derived from experience in the real world (Nelson, 1986). With respect to the Time-Line component of illness representation, physically healthy children are likely to acquire a cognitive representation of illness as an acute state. Feeling unwell, going to the doctor's, taking medicine and getting better are likely to constitute 'actions' within an 'extended script', consistent with an acute model of illness. This extended script may develop from a succession of individually or vicariously experienced acute illness episodes. In contrast, individual or vicarious experience of chronic illness is likely to provide children's illness scripts with an additional dimension, insofar as the possibility of a chronic Time-Line, in addition to the possibility of an acute Time-Line, increases the range of possibilities concerning illness representation. That is, an additional strand of Time-Line representation is incorporated into the illness script. On an applied note, it could be speculated that until this more sophisticated structure is achieved, it is unlikely that children will engage in preventative health behaviour, as the acute model of illness may predispose them towards reactive rather than preventative health behaviour.

Although the Piagetian and domain-specific approaches described above provide convincing explanations of children's general cognitive development and understanding of specific phenomena, with the exception of Nelson's (1986) script theory, the role of social interaction in facilitating children's cognitive development and understanding of specific phenomena remains largely unaddressed. That is not to say that cognitive-developmental researchers have ignored the social perspective. Although Bibace and Walsh (1981) emphasised the cognitive-developmental perspective, they also referred to situational variables as determinants of the conceptual sophistication of children's illness concepts. These variables included whether the form of questioning was spontaneous or structured, whether the disease under discussion was visible or invisible, and whether the child was asked about the cause of an illness, its cure, or the function of medicine. Similarly, although Campbell (1975) reported no significant association between parents' concepts of illness and the illness concepts of their children, it was suggested that when parents' concepts of illness relate to the child's experience of illness, the illness concepts of the parents might determine the illness concepts of the child. In this context of children's illness experience, it is worth considering how illness experience may promote children's understanding of illness.

1.6 Experience of Illness as a Determinant of Children's Illness Concepts

Several authors have emphasised the relevance of direct experience for children's development of illness concepts e.g., Eiser (1989), Eiser, Havermans and Casas (1993), Paterson et al. (1999). This emphasis constitutes the functionalist perspective. In defining what a functionalist perspective means, Eiser (1989) referred to its characterisation of knowledge development as proceeding through a series of novice-expert shifts.[10] Paterson et al. (1999) did not clearly define what they meant by a functionalist perspective beyond referring to the functionalists' emphasis of socio-cultural factors and experience. Perhaps the most appealing way of conceptualising this perspective is in terms of Keil's (1992) emphasis of the advantages for children of construing biological kinds in terms of functional relations. Presumably, implicit within this functionalist perspective, there is an assumption that illness experience leads to the development of strategies to resolve problems associated with illness, and that the development of adaptive strategies to cope with illness (and concomitant health and illness education) leads to advances in conceptual understanding. Insofar as such proposed advances in the conceptual understanding of illness are specific to the experience of illness, the functionalist perspective is also a domain-specific perspective.

Paterson et al. (1999) suggested that the sophisticated understanding of a specific disease that is derived from experience might be so domain-specific that it does not generalise to other diseases that have not been experienced. They also raised a concern that what is meant by illness concepts has not always been clearly defined in the literature. In some instances children have been asked about specific illnesses, in other instances about their general understanding of health and illness. In an attempt to address this issue and promote clarity and consistency within the literature, several authors have advocated the use of the illness cognition model (Lau & Hartman, 1983; Leventhal et al., 1997) (see

[10] In this respect, Carey's (1985) conceptual shift approach and Nelson's (1986) script theory may both be considered functionalist perspectives, and to consider this perspective independently of the cognitive-developmental perspective and the preceding discussion may be an artificial distinction. However, it may serve to emphasise, in contrast to the role of general learning and maturation, the role that experience is thought to play in promoting a conceptual shift.

chapter 2) as a framework for illness cognition research (e.g., Paterson et al., 1999; Petrie & Weinman, 1997).

The lack of clarity concerning the definition of illness concepts may be one of the reasons why previous research into the implications of personal illness experience for children's conceptualisation of illness has produced such mixed results. Some studies that have compared the illness concepts of healthy children and children with chronic illnesses have reported no difference in sophistication of the children's conceptualisation of illness (Myers-Vando, Steward, Folkins & Hines, 1979; Sherman, Koch, Giardina, Hymowitz, Siegel & Shapiro, 1985; Young, McMurray, Rothery & Emery, 1987). Even amongst these general findings however, there are inconsistencies. For example, on the basis of an inconsistency between chronically ill children's conservation performance and their understanding of illness causality, Myers-Vando et al. (1979) speculated that, in comparison with other cognitive-developmental tasks, illness experience may enhance children's understanding of illness concepts. Although Young et al. (1987) reported no significant difference in the mean 'stage' score of healthy children, children with acute lymphocytic leukaemia, and children with spina bifida, that was derived from the six stage categorisation system of Bibace and Walsh (1980), they suggested that, in comparison with the children's understanding of general health and illness concepts, experience of a specific illness or condition was associated with more sophisticated concepts concerning that experience. This latter finding is consistent with Paterson et al.'s (1999) suggestion that experience promotes the conceptual development of only very specific components within a domain.

In contrast to the general findings of the studies referred to above, other studies have found less sophisticated general knowledge about the body (Eiser, Town & Tripp, 1988), and less sophisticated beliefs about illness (Shagena, Sandler &

Perrin, 1988) among children with chronic illnesses. In comparison with healthy children, hospitalised children have been reported to have more sophisticated conceptualisations (Williams, 1978). In a study of children's knowledge about internal body parts, Clarke and Newell (1997) reported no significant difference between the knowledge of children with asthma and the knowledge of physically healthy children. Paterson et al. (1999) suggested that the discrepant findings were likely due to confounding and methodological factors such as small sample sizes, and a failure of investigators to control for age and intellectual status.[11] They also suggested that questions about illness should be derived from a specific theoretical conceptualisation of illness, whereas many past studies had focused on illness causality and questions of a seemingly arbitrary nature (Paterson et al., 1999).

In an attempt to resolve the issue, Paterson et al. (1999) conducted structured interviews with 7-14-year-old schoolchildren. These interviews incorporated the five components of illness representation derived from the illness cognition model (Lau & Hartman, 1983; Leventhal et al., 1997) and a Prevention component. Paterson et al. found that age, verbal intelligence, and socio-economic status were significant predictors of the sophistication of children's conceptualisation of colds and asthma. After controlling for demographic factors, they also found that children with a history of asthma demonstrated a greater sophistication of illness conceptualisation. They concluded that experience with illness, as well as cognitive developmental factors, should be considered in health promotion initiatives.

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[11] Perrin et al. (1991) also reported that, in comparison with physically healthy children, children with a chronic illness (either an illness that involved an orthopaedic condition or a seizure disorder) had a less sophisticated understanding of illness causality. However, Perrin et al. reported that when the children's general reasoning skills were taken into account, children with a chronic illness and physically healthy children had a similar understanding of illness causality.

In terms of healthy children's understanding of their blood, Eiser et al. (1993) reported on the relevance of children's direct experience for their ability to assimilate new knowledge. Twenty-five 3-year-olds, twenty-five 4-year-olds and twenty-seven 8-year-olds were interviewed about their understanding of the properties of blood and any occasions when they remembered seeing blood. There was considerable variability in children's reported experiences and their understanding of the function of blood. Eiser et al. hypothesised that experience would be beneficial when explaining concepts of blood to children, as they would be able to assimilate the new information within existing structures. A second study set out to test this hypothesis with the 3- and 4-year-olds of the earlier study. In comparison with children who reported no relevant previous experience, children who reported an incident in which they saw blood were more likely to recall new information about the function of red cells, white cells and platelets.

In a study of the implications of children's experience for their understanding of illness, Crisp, Ungerer and Goodnow (1996) emphasised the complementary processes of cognitive development conceptualised in terms of Piagetian theory, and the functionalist, domain-specific theories. The former link findings that as children grow older their understanding of illness becomes more sophisticated (Campbell, 1975), less concrete (Simeonsson, Buckley & Monson, 1979), reflects an increased differentiation between the self and the other (Bibace & Walsh, 1980), indicates a sense of increased perceived control over what the child perceives to be the cause of illness (Bibace & Walsh, 1980), is articulated in terms of internal body cues (Neuhauser et al., 1978), and is less likely to overextend the concept of contagion (Kister & Patterson, 1980). In comparison with children with no experience of illness, the latter predict greater understanding of illness among children with experience of illness (e.g., Paterson et al., 1999). Furthermore, in contrast to the suggestion that the effects of experience on concept development may be highly specific (Paterson et al., 1999; Young et al., 1987), Crisp et al. speculated that, in comparison with understanding of content areas unrelated to illness, the functionalist perspective may predict greater understanding of illness among children with experience of illness.

The participants in Crisp et al.'s (1996) study were all children with experience of hospitalisation. An 'illness experts' group was comprised of children with chronic illness (cystic fibrosis or cancer) and an 'illness novices' group was comprised of children with acute illnesses.[12] The 4-6-year-old and 7-10-year-old participants were asked several questions about the common cold, including questions about causality, consequences and recovery. The children's responses were coded using Bibace and Walsh's (1981) Piagetian framework. In a second study, to allow for the emergence of more sophisticated explanations, 7-10-year-old and 10-14-year-old participants were asked questions about illness in general. General cognitive development was assessed using conservation tasks and a test of receptive language.

Crisp et al. (1996) reported that both children's age and children's experience with illness predicted their understanding of illness causality. In general, (in comparison with younger children) older children and (in comparison with children with experience with acute disease) children with experience with chronic disease were reported to have a greater understanding of illness.

Given that relevant experience is a determinant of children's ability to develop cognitively sophisticated representations of illness, the question remains as to the mechanism whereby experience leads to understanding and sophisticated

[12] Yoos (1994) reported how experience of illness leads not only to increased knowledge of facts concerning the illness, but also to differences in the relationship between illness representation components. Experts were suggested to have at their disposal a more differentiated and cohesive system of knowledge that is organised around the principle of physiology. In contrast, novices' reasoning about illness was suggested to rely on uni-dimensional conceptualisations of causality and surface features of concepts.

representation. Slaughter et al.'s (1999) idea about the mutually supportive nature of a coherent system of biological concepts, in combination with Kalish's (1999) ideas about the role of concept differentiation stemming from experience may explain the process of conceptual development with respect to illness.

Keil (1992) suggested that children's development of biological knowledge initially involves the development of a conscious awareness of how functional relations are linked with biological kinds, and that such an awareness develops from an implicit tendency to associate functional relations with biological kinds. This implicit tendency was suggested as a guiding determinant of the exploration and investigation of biological phenomena as well as the development of knowledge in the specific domain of biology; implicit congruence between specific modes of construal and different kinds of real world phenomena may lead to distinct ways of construing different phenomena and the development of different domains of knowledge. Beyond such domain specific and congruent modes of construal, experience may further determine the extent of differentiation and sophistication of specific concepts within any given domain (Eiser et al. 1993; Paterson et al., 1999). As previously suggested, it may be that experience with illness prompts children to develop adaptive strategies to solve specific illness problems. This would lead to the development of cognitively sophisticated and domain-specific conceptual understanding.

As knowledge within a domain such as biology is developed through a specific mode of construal (Keil, 1992) it is also likely that a degree of coherence would be found between different concepts within the domain, a suggestion consistent with Slaughter et al.'s (1999) reports of coherence among children's biological concepts. It may be, however, that the social constructivist theories of cognitive development can also provide some answers. Indeed, Kalish (1999) suggested that children's understanding of biology might be linked to their early concepts of contagion and contamination, which are modified and developed through an interaction of experience and culture. In this respect, in the context of discussing beliefs about natural phenomena or bodily states as causes of illness, Williams (1978) suggested that children's conceptions of illness causality were likely to match those of their caregivers. In this context, experience of illness and its treatment would be likely to involve the provision of specific information that may modify the child's beliefs. As in Nelson's (1986) script theory, this places real world experience and social interaction at the hub of children's cognitive development.

1.7 Social Interaction as a Determinant of Children's Illness Concepts

Social constructivists such as Vygotsky explain children's cognitive development as a process involving the acquisition of culture and knowledge through social interaction (Das Gupta, 1994). Children are hypothesised to develop concepts and, in particular, abstract scientific concepts, through internalisation of social interactions and through repeated experience with similar situations (Das Gupta, 1994). Experience and interaction with the environment are suggested to be insufficient as determinants of children's higher levels of scientific, cognitive sophistication. Rather, these are suggested to be determined through adults' structuring of situations and experience (Au et al., 1999; Das Gupta, 1994; Nelson, 1986). This social constructivist position is particularly relevant to children's acquisition and development of biological concepts and concepts of illness.

As far as the social context of health and illness are concerned, Wilkinson (1988) described how a distinction should be made between a child's knowledge of fact and the interactional component of health and illness behaviour. These two components are thought to contribute to the development of children's views of illness. One form of discourse takes place primarily in a social context, and relates to children's complaints about their discomforts and the effectiveness of that form of discourse in eliciting responses from significant others. The second form of discourse relates to the language that children use to express knowledge about illness and the nature of discomforts.

If, as Dunn and Brown (1994) suggested, the experience of negative rather than positive affect leads to family discussion of emotion and internal states, children with experience of illness are likely to engage in a greater amount of discussion about their illness, and because of this, may be able to talk in greater detail about their illness. Experience with illness may facilitate a greater sophistication of illness representation through providing a context for the discussion of internal states. This in turn may facilitate children's accurate perception and description of their illness. Such a position supports the suggestion that illness experience, in the context of social interaction, is the main determinant of the sophistication of children's cognitive representation of illness. Sherman et al. (1985) reported that a significant association between parents' and children's understanding of the child's specific illness was dependent on the child's age. To the extent that discussion about the details of an illness is likely to take place between parents and older children, this finding lends further support to the idea that knowledge about illness is socially constructed. The study reported in chapter 7 considers the extent to which family discussion about asthma promotes children's conceptualisation of the disease.

The foregoing discussion suggests that the different approaches to conceptualising children's development of specific beliefs about illness and understanding of illness concepts have emerged from different theoretical positions. Therefore, they each emphasise different aspects of the structure and process of cognitive development. However, these differences reflect complementary approaches that are inextricably intertwined and are differentially suited for the discussion of different aspects of health, illness and conceptual understanding. These apparent differences in approach may well be less significant when the researchers' aims are considered. In this respect, previous and contemporary research, within the domain of health care provision for children, encourages practitioners to work towards enhancing the provision of services for children, children's involvement in their own care, and children's involvement in decision-making concerning the care they receive.

1.8 Summary

Several different perspectives on children's understanding of illness were introduced. These included research that developed from Piagetian explanations of cognitive development, that placed children's illness conceptualisation within a framework that emphasised the development of logical operations (e.g., Bibace & Walsh, 1980; 1981), and research that has examined different aspects of concept formation, including innate predispositions (e.g. Keil, 1994), conceptual shift (e.g., Carey, 1985), the role of experience (e.g., Paterson et al., 1999), the role of social interaction (e.g., Nelson, 1986), and the role of education and learning (e.g., Au et al., 1999).

Chapter 2 Illness Cognition

2.1 Introduction

Traditional research into the psychology of health and illness has focused primarily on the psychosocial aspects of illness (e.g., Drotar, Doershuk, Stern, Boat, Boyer & Matthews, 1981; Kashani, Konig, Shepperd, Wilfley & Morris, 1988; MacLean, Perrin, Gortmaker & Pierre, 1992; Marteau & Johnston, 1986; Mattson, 1975; Mrazek, Schuman & Klinnert, 1998; Nassau & Drotar, 1995; Nocon & Booth, 1991; Norrish et al., 1977; Tavormina, Kastner, Slater & Watt, 1976). Although these descriptions of the general signs and symptoms of a particular illness are of theoretical and clinical utility, recent research has sought to reach an understanding of the patients' perspective e.g., Petrie and Weinman (1997). In so doing, research into the psychology of health and illness has developed to include illness cognition (e.g. Abraham et al., 1998; Bishop, 1991; Bishop, Briede, Cavazos, Grotzinger & McMahon, 1987; Bishop & Converse, 1986; Goldman et al., 1991; Hampson, Glasgow & Zeiss, 1994; Jensen & Karoly, 1992; Lacroix, Martin, Avendano & Goldstein, 1991; Lau, 1997; Petrie & Weinman, 1997). Specifically, there has been a greater emphasis on the way in which health behaviour is motivated (Leventhal et al., 1997) and the processes involved in illness cognition (Bishop, 1991; Lau & Hartman, 1983; Leventhal et al., 1997). This research has tended to follow three strands: (i) conceptualisation of illness cognition in terms of illness prototypes e.g., Bishop and Converse (1986), (ii) conceptualisation of illness cognition in terms of illness schemata e.g., Lacroix (1991), and (iii) development of the self-regulatory model e.g., Petrie and Weinman (1997). The focus of this chapter is a discussion of the three strands of research, and how the self-regulatory model, in particular, has been developed in recent years. The chapter concludes with a consideration of how cognitive representations of illness may be acquired and developed.

2.2 Illness Prototypes

Bishop and Converse (1986) investigated the relationship between disease prototypes and symptom sets. They suggested that, people develop illness prototypes through experience with illness, and that such prototypes are often based on an acute model of illness. In an investigation of prototypicality effects in processing illness information, in comparison with low typicality sets, Bishop et al. (1987) found that participants took less time to reach decisions about the disease identity of high prototypicality sets.

To clarify the role of illness prototypes in lay-diagnosis, and laypersons' use of illness representations, Lalljee, Lamb and Carnibella (1993) considered how participants' grouped illnesses according to perceived similarity, and examined the content of illness representations that were associated with a representative illness from different clusters of illnesses. It was suggested that particular illnesses were grouped together according to a variety of determinants, including perceived cause, seriousness and anatomical location. Lalljee et al. also referred to the significance of the participants' perception of a typical sufferer, for example, the sufferer's cultural background, or the age of onset of a disease.

In the context of individuals' interpretations of symptoms, Laljee et al. (1993) considered further the implications of participants' belief that certain people are susceptible to particular illnesses. Although previous research into illness prototypes had emphasised the role of symptoms (Bishop et al., 1987), Lalljee et al. (1993) reported that information about the sufferer (and perceived cause) was at least as relevant to diagnostic decisions as was information about symptoms. They suggested that only when incongruence was perceived between the sufferer and the symptoms were diagnoses based primarily on information about symptoms.

2.3 Illness Schemata

In discussing illness cognition, other researchers have referred to patients' illness schemata (e.g., Lacroix et al., 1991). These have been referred to as cognitive structures that consist of four components: (i) a belief in the interdependence of physical and psychological functions, (ii) a set of signs and symptoms consistent with that belief, (iii) a theory about the mechanism of the relationship between the signs and symptoms of illness, and (iv) ideas about what action should be taken to restore health (Lacroix, 1991). Mainly concerned with the consistency between patients' beliefs about illness and health care professionals' beliefs about disease, Lacroix et al. (1991) emphasised the role of patients' illness schemata as determinants of adaptation to illness. They reported that, in comparison with less well-informed patients, chronic respiratory patients who were well-informed about their illness had higher levels of physical, psychological and social functioning. Their conclusion was that an accurate understanding of illness has implications for functional prognosis.

Understanding about an illness may also have implications for patients' health-related behaviour. Although patients were reasonably proficient at grouping symptoms on the basis of a common underlying aetiology, their explanation of the causes of those groupings were often at variance with the explanations of health care professionals (Lacroix et al., 1991). The rationale for a particular health behaviour recommendation is usually consistent with the medical explanation of illness causality. If that explanation differs significantly from the explanation of the patient, the adoption and effectiveness of illness management strategies may be seriously compromised.

2.4 The Self-Regulatory Model and the Cognitive Representation of Illness

Early models of compliance behaviour prompted research specifically concerned with the cognitive representation of illness (Leventhal, Meyer & Nerenz, 1980). Leventhal et al. discussed how, in order to understand patient compliance, it is necessary to understand what illness and treatment theories guide the behaviour of patients. They suggested that an incorrect assumption that patients share the same model of illness and its treatment as their attending health care professionals may have serious implications for the success of any given health intervention. Effective interventions are likely to develop from an on-going consideration of the model or representations of illness and its treatment that patients develop or maintain over the course of an illness. Leventhal et al. linked these representations with both the objective appraisal of events surrounding illness and the subjective, emotional experience of illness and its treatment. It is these cognitive and affective aspects of illness representation that Leventhal et al. believed were the determinants of the goals that patients set, the coping strategies that they adopt, and the perceptions that they have concerning the effectiveness of their coping behaviour. The main point of Leventhal et al.'s discussion was that the way in which patients perceive or represent their illness determines their behaviour, and that by reaching an understanding of the illness representations of patients, it is possible to reach an understanding of patients' behaviour.

Developing these ideas further, Leventhal et al. (1984) emphasised that people are motivated to regulate or reduce their health-related risks, and to act to reduce those health threats in ways consistent with their perceptions of them. They emphasised the role of both cognition and affect in the processing of illness information and referred to an active, self-regulating, information-processing system. This system was suggested to be responsible for the generation of illness representations (Scharloo & Kaptein, 1997).

The four basic assumptions on which Leventhal et al.'s (1984) self-regulating model was based were (i) active processing, (ii) parallel processing, (iii) stages in processing, and (iv) hierarchical processing. Active processing refers to the active construction of representations based on previous experience, emotional reactions and coping. In this way health-related experiences are organised into a system of representation. Parallel processing refers to the two component pathways of the model; one pathway leading to the construction of an objective representation of the health threat and a coping plan for its management, a second leading to an emotional response to the problem and a plan for the management of emotion.

In developing a model based upon the three recursive stages of representation, coping and appraisal, Leventhal et al. (1984) described how the first stage involves the construction of a representation of the health threat and its associated affect. The second stage involves the development and execution of plans to cope with both the health threat and the emotion, the coping strategies being in part determined by the nature of the illness representations. Based on the consequences of the coping stage, the third stage of appraisal determines how effective the coping strategies have been in helping the individual to achieve their goals. The outcome of the appraisal stage may feed back into the representation and coping stages, to consolidate or modify the representations and coping plans.

Hierarchical processing refers to the hypothesised dual level of processing i.e., concrete and abstract. In Leventhal et al.'s (1984) self-regulating model, abstract processing referred to the processing of abstract information that may in itself be objective, for example, being told that one's peak flow has returned to a normal level after an acute exacerbation of asthma. Concrete processing referred to the processing of what are essentially sensory perceptions. For example, feeling anxious about the possibility of another acute exacerbation, and the subjective perception that one's peak flow may not in fact be what it should be. Leventhal et al. suggested that abstract processing might determine problem-based representations whereas concrete processing (and perceptions) may determine emotional response.

2.5 Components of the Cognitive Representation of Illness

In recognition that different components of illness representation may be implicated in illness behaviour and patient coping, researchers have attempted to clarify the precise nature of illness representation (e.g., Lau & Hartman, 1983). Research to date has identified five components of illness representation: (i) Identity (the specific symptoms of a disease and its label), (ii) Time-Line (the time taken for an illness to develop and its duration), (iii) Consequences, (iv) Cause, and (v) Cure/Controllability (Lau & Hartman, 1983; Leventhal et al., 1997).[1] Leventhal et al. (1997) noted that the five components of illness representation are organised into sets. They suggested that people have at least three different types of illness model associated with (i) acute illness, (ii) cyclic illness, and (iii) chronic illness.

The five-component representation of illness has received empirical support from studies that have employed a variety of research methodologies. These include interviews with patients (Lau & Hartman, 1983), self-report assessments with patients and healthy controls (Weinman, Petrie, Moss-Morris & Horne, 1996), and experimental studies with healthy participants (Bishop et al., 1987).

The main aim of Lau and Hartman's (1983) study was to determine beliefs about common illnesses, and to relate those beliefs to health beliefs and health-related

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[1] In Bishop et al.'s (1987) study of prototypicality effects in processing illness information, participants' responses to a question about what else may be associated with specific symptom sets supported the validity of the Identity, Time-Line, Cause, Consequences and Cure/Control dimensions of illness representation.

behaviour. They suggested that ideas about the causes of illness and recovery (and the provision of a disease label) were the main components of student participants' beliefs about non-serious, common illnesses. Although some participants did refer to the Time-Line and Consequences components, Lau and Hartman suggested that these dimensions might be less salient for patients with minor illnesses whereas for patients with a serious or chronic illness they may be integral features of the illness representation. In support of the latter suggestion, in comparison with a group of physically healthy children, children with asthma demonstrated a greater sophistication of the Time-Line concept (Paterson et al., 1999).

Lau, Bernard and Hartman (1989) investigated the consistency of the five dimensions of illness representation over successive illness episodes. When college undergraduates were asked an open-ended question about their most recent experience of a cold and other common illnesses, participants most often referred to Identity (label and symptoms). Time-Line also featured in many respondents' reports as did, to a lesser extent, Cure (controllability), Cause and Consequences. Lau et al. suggested that, although there was strong evidence for the generality of the components of illness representation, in describing any single illness episode, respondents were unlikely to refer to all five components. A degree of consistency in pattern of representation between illness episodes was also noted, as was an association between beliefs about the controllability of a disease, personal responsibility for recovery from illness, and beliefs about self-control over health.

Healthy preschool children have also been reported to be able to identify the same five components of illness representation, although their concepts of cure were more sophisticated than their concepts of cause (Goldman et al., 1991). The study group children were 4-6-year-olds, and on a methodological note, it was suggested that 4-6-year-olds have sufficient verbal ability to participate in interviews and report meaningful data, and to use language and mental representation to understand their experiences. Goldman et al. suggested that 4-6-year-olds experience a wide range of common illnesses from which a representation of illness can be constructed. The children were asked specific open-ended questions about each illness dimension. The Cause dimension was assessed using Perrin and Gerrity's (1981) six category coding scheme: (i) "don't know" responses, (ii) superficial responses, (iii) reference to concrete rules and prohibitions, (iv) reference to a causative agent and its internalisation, (v) links between a causal agent and a body's response, and (vi) reference to internal systems and physiological mechanisms. Although the majority of children provided a causal explanation of illness, few demonstrated a clear understanding of a relationship between an external agent and an internal bodily process.

The Cure (controllability) dimension was categorised according to the locus of the curative agent (external, internal or a combination of both). Goldman et al. (1991) reported that almost all children reported strategies for recovery and suggested that children may have a greater sense of their role in remediation than in the prevention of illness. This is relevant to Hunt, Jordan, Irwin and Browner's (1989) suggestion that patients' health-related behaviour is mainly concerned with the control of acute symptoms rather than with maintaining health. Goldman et al. (1991) suggested that children's experience of illness, and specifically their directed behaviour during an illness episode, determines differences between children's perceptions of their role in promoting recovery, and their perceptions of their role in causing or preventing illness. They suggested that the different degrees of perceptual salience might be responsible for differences in the quality of different dimensions of illness representation.

Expected duration of illness (Time-Line) was categorised according to Piagetian theory: (i) no response, (ii) reference to subjective experience and measures of time that were discrepant within a set of questions, and (iii) reference to an objective measure of time that was consistent within a set of questions. Goldman et al. (1991) reported that virtually all of the children conveyed an understanding that the types of illness asked about resolved within "a short time" and that in defining "a short time", fewer children referred to a subjective or variant time than to an objective and invariant time. On the basis of this finding, Goldman et al. (1991) suggested that common illnesses are perceived to have a short time-line. This is consistent with Meyer et al.'s (1985) suggestion that patients' representations of illness are initially based on an acute model of illness.

The Consequences dimension was assessed using Campbell's (1975) Principal Themes Defining Illness Scale (see page 15). Most of the children reported consequences of illnesses in terms of somatic states; illnesses were often defined in terms of symptoms, a finding consistent with Bishop et al.'s (1987) suggestion that symptoms are the main feature of patients' representations of illness. It was suggested that children associate specific illness identity labels with particular sets of symptoms. This is relevant to Baumann, Cameron, Zimmerman and Leventhal's (1989) suggestion of label-symptom symmetry in adults i.e., that when provided with health-relevant information, or when symptoms are experienced, individuals look for symptoms, or disease labels respectively, that are consistent with their beliefs about the nature of the health threat.

2.6 Illness Cognition Research with Special Populations

More recently, illness cognition research has considered how the cognitive representation of illness is associated with illness self-management behaviour and the implications for health maintenance (Bradley, Gamsu, Moses, Knight, Boulton, Drury & Ward, 1987; Hampson et al., 1994; Jensen & Karoly, 1992; Naea De Valle & Norman, 1992). Specific components of illness representation have been reported to be associated with a variety of health and illness behaviours. For example, beliefs about disease Identity and compliance with treatment regimens (Leventhal et al., 1984), beliefs about Time-Line and whether or not patients continue with a treatment programme (Meyer et al., 1985), and beliefs about Controllability and adherence to treatment regimens (Meyer et al., 1985).

2.7 Components of Illness Representation as Determinants of Health and Illness Behaviour

Leventhal et al. (1984) suggested that beliefs about disease Identity are created through an integration of abstract and concrete information. However, the concrete perceptions of symptoms were suggested to be the determinants of patients' health management behaviour. Meyer et al. (1985) also suggested that patients attempt to define illness in terms of concrete perceptions and that, in comparison with abstract representations of disease, concrete perceptions may have a greater influence on health-related behaviour. Patients who believe that a treatment is effective in controlling their perceived symptoms may be more likely to adhere to the treatment regime.

In this respect, hypertension is a disease of particular interest (Meyer et al., 1985). First, personal beliefs about hypertension are likely to be important because the disease is asymptomatic. Second, effective control of blood pressure requires that patients adopt specific health-related behaviour such as taking regular medication, losing weight and changing their diet. These factors made it possible to investigate how illness representations were associated with the adoption and maintenance of health behaviour.

Consistent with the self-regulatory model of Leventhal et al. (1984), Meyer et al. (1985) began their study from three assumptions that they believed were associated with patients' health and illness behaviour. First, patients are motivated to reduce or avoid health threats. Second, patients define illnesses in terms of concrete, perceptual cues as well as disease labels. Third, concrete perceptions of a disease exert a strong influence on patient behaviour. If, as Lau and Hartman (1983) suggested, experience of illness episodes has a cumulative effect on health beliefs, patients with hypertension could be expected initially to try to assimilate hypertension to their models of previous common, acute illnesses. On the assumption that common, acute illnesses typically follow the pattern of diagnosis (associated with signs and symptoms) followed by treatment and the alleviation of signs and symptoms (associated with cure), it is reasonable to assume that patients also expect this model of illness to apply to hypertension. Signs and symptoms associated with consultations during which blood pressure is taken and diagnosis made, may be perceived as signs and symptoms of hypertension, and situational contingencies with signs and symptoms may be perceived as the cause of hypertension. For some patients, use of medication may be associated with a reduction in signs and symptoms. For other patients, use of medication may be associated with an increase in symptoms. The extent to which there is a contingency between medication use and perceived cause, and between medication use and perceived signs and symptoms is likely to determine patients' beliefs about treatment efficacy, and the likelihood that health-related behaviour is maintained.

To test these hypotheses, Meyer et al. (1985) interviewed patients with hypertension and normotensive control patients, to elicit their views about hypertension. Meyer et al. emphasised attempts to obtain from patients descriptions of their personal views about hypertension and to distinguish those views from what patients had been told about hypertension, and what patients believed to be generally true of hypertension. Patients who had been in continuous treatment for between three months and fifteen years were also asked to give details about adherence to treatment regimens; this enabled a differentiation of patients who took medication as prescribed, patients who randomly and infrequently missed medication, and patients who systematically altered their treatment regimen.

Meyer et al. (1985) reported that 46% of normotensive control patients, 71% of patients in treatment for hypertension for the first time, 92% of patients who had been in continuous treatment, and 94% of patients who had dropped out of and then returned to treatment identified symptoms associated with hypertension (Identity). Meyer et al. noted a distinction between patients' abstract views about hypertension that were consistent with medical views of the disease, and patients' personal beliefs based on subjective experience.

Although research such as that of Meyer et al. (1985) suggests that perceptions of symptoms are associated with specific beliefs about illness, Leventhal et al. (1984) also suggested that the identity of an illness is of relevance to health-related behaviour beyond concrete perceptions of symptoms, citing as evidence the compliance with treatment of asymptomatic patients with cancer.

What is of interest is the extent to which the label or the symptom determines health-related behaviour. For example, is a diagnosis of asthma sufficient to promote health maintenance behaviour or are symptoms a necessary determinant? In contrast with asymptomatic illnesses such as hypertension, asthma is a symptomatic illness, and an awareness of symptoms may contribute to effective management by informing decisions about stepping up and stepping down medication (The British Guidelines on Asthma Management, 1997). However, given that the use of preventative medication now forms part of the asthma management regime, asymptomatic illness states are likely to be experienced. The question remains as to whether, in such instances, the label of asthma is sufficient to maintain patient adherence. Specifically, to what extent do patients with well-controlled asthma remain adherent with a preventative medication regime? Determinants of continued adherence are likely to include the efficacy of the disease label in promoting health-related behaviour, the previous experience of symptoms, the duration of an asymptomatic state, and the extent to which adherence is perceived as burdensome or beneficial. For continuing treatment hypertension patients, a belief that medication affected symptoms (Cure/Control) was associated with adherence to medication regimens (Meyer et al., 1985). In contrast, a belief that medication had no effect on symptoms was associated with nonadherence.[2]

Leventhal et al. (1984) also described how patients expect consistencies between illness representations and treatment. Of particular relevance was the observation that patients with cancer undergoing metastatic or adjuvant treatment, and who linked illness and treatment through an acute model of illness, experienced considerable distress when initial therapy was particularly effective. Leventhal et al. suggested that the reason for this distress was that the patients with perceptions of being cured, either through surgery or through effective metastatic treatment, perceived an inconsistency between their notion of illness, cure, and having to continue with a distressing treatment. Patients were suggested to have an acute model of illness and parallel expectations about treatment. Such an idea is of particular relevance for patients with asthma, who although they do not have to continue with a distressing treatment, do have to continue with a treatment beyond what could be described as the achievement of effective control and becoming asymptomatic. To what extent do patients with well-controlled asthma experience distress at having to continue with treatment? Hyland, Ley, Fisher and

[2] Adherence to treatment regimens was associated with good control of blood pressure.

Woodward (1995) suggested that for some patients with asthma, the use of preventative medication might be associated with distress despite improvements in lung function. Although the inconvenience of treatment and medication-related factors, such as the taste of the inhalers, may be the determinants of patients' distress concerning preventative treatment, patients' beliefs about the time-line of asthma may also be of relevance. Myer et al. (1985) suggested that Time-Line beliefs about hypertension were a good predictor of patients' remaining in treatment; patients with a belief that hypertension was a chronic disease were the least likely to drop out of treatment.

The above findings suggest that it would be worthwhile to consider the illness and treatment representations and psychological well-being of patients with asthma. The third and fourth studies, reported in chapter 7 and chapter 8 respectively, examined the beliefs about asthma and psychological well-being of a group of children with a range of asthma severity.

2.8 Investigating the Cognitive Representation of Illness

Recent illness cognition research (e.g., Petrie & Weinman, 1997) has to a large extent been fuelled by the development of the Illness Perception Questionnaire (IPQ) (Weinman et al., 1996). The IPQ is a theoretically-derived questionnaire assessment of the cognitive representation of illness. It consists of five subscales corresponding to the illness representation components of disease Identity, Time-Line, Cause, Consequences and Control/Cure. Weinman et al. reported data to support the concurrent, discriminative and predictive validity of the questionnaire. Specifically concerning patients with asthma, Control/Cure scores of patients with severe asthma correlated with scores on an asthma-specific version of the Multidimensional Health Locus of Control Scale (MHLC) (Wallston, Wallston &

DeVellis, 1978); Control/Cure scores were positively correlated with the MHLC Internal scale and negatively with the MHLC Chance scale.

2.9 Illness Representations and Psychosocial Aspects of Illness

Lau (1997) suggested that patients with a chronic disease have multidimensional representations of health that involve beliefs about physical, emotional and social well-being. Consistent with this view, recent illness cognition research has started to investigate the associations between psychosocial aspects of specific illnesses and illness representation components. For example, Heijmans (1999) examined the relationship between illness representation, coping strategies, and adaptive functioning in a group of patients with Addison's disease. Illness representations distinguished between patients who perceived Addison's disease to be a disease of high seriousness and those who perceived Addison's disease to be a disease of low seriousness. This ‘seriousness’ variable was a significant predictor of adaptive physical functioning, social functioning, mental health and general vitality. Similarly, osteoarthritis patients’ beliefs about the symptoms and seriousness of their condition were associated with a variety of health outcome indicators including quality of life (Hampson et al., 1994); patients with higher scores on symptoms and seriousness reported higher levels of self-management, greater utilisation of medical services and a poorer quality of life.

2.10 The Acquisition and Development of Cognitive Representations of Illness

Leventhal et al. (1984) described three sources of information that contribute to the formation of illness representations: (i) a generalised pool of knowledge about illness that exists within a culture, (ii) social communication about illness including communication with health professionals, and (iii) personal experience of illness episodes. Cultural knowledge about illness is suggested to include ideas about the nature of illness that to a large extent are consistent with the culture's medical system. For example, in the West, ideas about the nature of illness are consistent with the biomedical system that often represents illness as acute and requiring short periods of treatment that are usually effective. Wilkinson (1988) also discussed the relevance of cultural beliefs to illness representations and emphasised the distinction between naturalistic and personalistic medical systems. Naturalistic medical systems were linked with systems in which the patient decides what is the cause of the illness and seeks assistance with the cure. Personalistic medical systems were linked with systems in which consultation with a professional is considered necessary for the divination of cause and in which treatment can be delegated to others.

The influence of significant others and health professionals in contributing to the illness representations of patients may operate through social comparison processes, through sharing of information, and through patient education (Lacroix, 1991; Leventhal et al., 1984; Radley, 1994). Linn, Linn and Stein (1982) suggested that patients' beliefs about causality are framed within the context of their life experiences and interactions with others. Specifically, Linn et al. suggested that at least in part, patients' beliefs about the causes of their illness are determined by their interactions with other individuals who share the same life experiences and behave in similar ways and yet who remain healthy. Health care professionals may also be implicated in the direct and indirect provision of information about the causal antecedents of an illness (Naea De Valle & Norman, 1992). Questions that are asked about patients' lifestyle, or the discussion of lay explanations of causality, may prompt attributions about personally relevant causal antecedents by stimulating an autobiographical search for the presence of previously implicated causal factors (Naea De Valle & Norman, 1992). As Linn et al. (1982) suggested, perceived consistency between patients' recollections and implicated or hypothesised causes may then determine patients' specific causal attributions for their individual circumstances. Naea De Valle and Norman (1992) emphasised that rather than imposing a set of causal attributions onto patients, health care professionals should make therapeutic interventions more effective through discussion with patients about causal antecedents. Such discussion would allow patients to reframe existing beliefs about illness causality and to construct a set of causal attributions that may motivate and encourage behaviour change that is likely to promote recovery.

Leventhal et al. (1984) suggested that illness representations may also be modified on the basis of inferences made from the behaviour of health professionals during a consultation. For example, questions such as "How do you feel?" may serve as implicit conveyors of expectations that because of an illness a patient should feel different even if the disease is asymptomatic. Similarly, when a patient is asked questions about the potential side-effects of a treatment, unless clearly specified as questions about side-effects, such questions may be interpreted as questions about an illness with contingent implications for the representation of the illness.

Drawing on the above, it is clear that the experience of illness may have implications for the cognitive representation of illness. Personal experience of illness may lead to the formation and modification of illness representations through the recursive stages of representation, coping and appraisal that feed into the illness knowledge system (Leventhal et al., 1980). Successive illness episodes are suggested to gradually confirm or modify the prototype representations (Meyer et al., 1985) and allow for the development of associations between specific illnesses, specific symptom sets, and beliefs about what action to take to restore health (Lau, 1997; Leventhal et al., 1980).[3] Lau and Hartman (1983) suggested that illness beliefs are developed and modified through the cumulative effect of illness experience. Consistent with this suggestion, Meyer et al. (1985) reported that at a 6-month follow-up interview, newly treated patients with hypertension had modified their illness representation of hypertension as an acute disease to one of hypertension as a chronic disease. Associations and contingencies between situational variables, perceived somatic cues, and treatment may also determine illness representations as patients strive to make sense of their illness and its treatment (Meyer et al., 1985).

The research of Paterson et al. (1999) led to the conclusion that in addition to cognitive developmental factors, experience with illness was a determinant of children's cognitive representation of illness. In comparison with physically healthy children, children with asthma had a more sophisticated understanding of the Cause, Time-Line, and Controllability of asthma. However, there were no differences in the sophistication of children's conceptualisation with respect to the Identity of asthma, its Consequences or its Prevention.[4] Paterson et al. suggested three reasons to explain why the Consequences and Prevention dimensions of asthma representation were less affected by experience of asthma: (i) abstract concepts of illness such as prevention develop more slowly than ideas about cause (Rosenthal et al., 1995) and symptoms (Schmidt & Weishaupt, 1990), (ii) emotional correlates of reasoning about consequences and prevention may affect learning in these domains, and (iii) the consequences of asthma were likely to be fairly salient for all the children who participated in the study because of health

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[3] There is a similarity between this view of the development of illness prototypes and Lacroix's (1991) description of illness schemata.

[4] These findings suggest that the specific focus of a research investigation is also likely to influence the pattern of results obtained from interviews with different individuals about illness.

promotion efforts and the children's subsequent familiarity with this aspect of asthma.

Schmidt and Weishaupt (1990) also reported developmental differences in children's concepts of illness causality; in comparison with preschoolers, elementary schoolchildren had more sophisticated ideas about the causes of illness. Schmidt and Weishaupt suggested that children are able to make use of information pertaining to the concrete aspects of common illnesses and minor injuries, for example symptoms and treatment, before they are able to represent the abstract aspects, for example causality. They also concluded that the sophistication of children's ideas about illness were not disease independent. The sophistication of children's ideas appeared to be linked with the identity of a disease, or perhaps more precisely, with the extent of children's experience with a disease. For example, children are likely to have more experience with colds and minor injuries than with measles. The pattern of results suggested that insofar as cold and minor injuries were concerned, only ideas about causality were associated with developmental trends. In comparison to this apparent sophistication of young children's ideas about the symptoms and treatment of a cold and minor injuries, preschoolers' ideas about the symptoms, cause and treatment of measles, a less common illness, were less sophisticated than those of elementary schoolchildren.

Taken together, the research of Paterson et al. (1999), Rosenthal et al. (1995), and Schmidt and Weishaupt (1990) suggest that children's ideas about symptoms and treatment are the earliest aspects of illness representation to develop. Ideas about cause develop later, followed by ideas about prevention. That in comparison with other components of illness representation, ideas about cause and prevention are at a similar conceptual level is perhaps not surprising, given the cause-prevention contingencies of disease management and their potential redundancy in a system of other-managed care. When the transition is made from other-managed care to self-management, while an understanding of cause-prevention contingencies are not essential, it may be said that an accurate understanding of illness prevention is contingent upon an accurate understanding of illness causality. For this reason, it may be expected that an understanding of prevention would proceed from an understanding of causality. The extent to which children are involved in the management of their illness, and the extent to which they are informed about different aspects of illness, would likely determine the extent to which their cognitive representations of illness develop beyond simple symptom and treatment dimensions.

In considering further how these differences in the cognitive representation of illness may develop, and their association with experience of illness, it is worth considering again the social constructivist perspective that was introduced in chapter 1.

Radley (1994) emphasised the socio-cultural construction of health and illness representations and in discussing the experience of chronic illness, stated that children with chronic illness learn about their illness from their parents. Although no empirical evidence was cited in support of this view, in this model of the formation of illness representations it is the parents of the child who teach the child with a chronic illness not only about what to do with symptoms but also how to speak about their disease with others. Radley (1994) emphasised the functional nature of this tuition that provides a system of illness representation and discourse that aims to minimise the child's experience of stigma.

Expanding the notion of tuition to include family discussion, it is plausible that the caregivers' awareness of the child's illness is a determinant of the tuition the child receives and the opportunities for family discussion of illness states. This is likely to be of particular relevance for children with illness characterised by mild symptoms rather than overt signs. For example, in discussing individual decisions about health status, Radley (1994) referred to how perceptions of physical sensations may or may not be interpreted as indicative of disease, and how perceptions of health and illness were related to the tendency of individuals to accommodate to physical sensations, particularly those sensations that may be experienced on a daily basis. It was suggested that if specific sensations were perceived by an individual to be a normal part of daily living, they would be unlikely to interpret those sensations as symptoms of a disease and would not refer to them when asked about their individual experience of illness. The implications are that a child with mild asthma may habituate to a respiratory impairment and remain undiagnosed and consequently untreated. In such instances, the sensitivity of the parents to the respiratory status of the child would determine the accurate identification of specific respiratory states and the subsequent labelling of contingent sensations as symptoms.

Several researchers have considered concordance in family health cognitions (e.g., Bush & Iannotti, 1988; Khampalikit, 1983). Bush and Iannotti (1988) reported small but significant associations between mothers' and children's concerns about illness, attributions of illness, perceptions of vulnerability, perceptions of severity, and health locus of control beliefs. They reported no association between a disposition toward use of medication and perceptions of the positive aspects of medication use. Children with asthma and their mothers have also been reported to have similar perceptions of the severity of the child's asthma and the symptoms associated with acute exacerbations, similar beliefs about the psychological impact of asthma in terms of the child's happiness, and similar beliefs about the impact of asthma on social life and career opportunities in the future (Khampalikit, 1983). There was no association reported between mothers' and children's belief about the life-threatening potential of asthma (Khampalikit, 1983).

With respect to families of children with cystic fibrosis, Burton (1975) identified several factors that determined children's ability to talk about their illness, including the general level of communication within the family and the degree of emotional discomfort. The extent of parental communication affected that of the child, and the degree of knowledge about the disease that was displayed by the child. The child's level of communication about their illness was significantly related to the parents' level of understanding concerning the disease.

In contrast to the suggestion that family discussion is the main determinant of children's beliefs about illness, Chen (1986) suggested that children acquire health behaviour through observation of their parents' behaviour. For children with asthma, it may be that a family history of asthma, and contact with family members who engage in asthma-related preventative behaviour lead to the child's acquisition of the same behaviour with contingent positive health outcome. However, a child's adoption of their parents' health-related behaviour may not necessarily translate into concordance between the parents' and the child's health beliefs. As suggested above, belief concordance is likely to develop through family discussion. The studies reported in chapter 7 and chapter 8 improve our understanding of the beliefs about asthma of children with asthma and their parents, and the implications of concordance in beliefs of parents and their child about asthma. The conclusions formed the basis of a discussion as to how children with asthma may acquire their beliefs about asthma, and how those beliefs may influence the relationship between illness severity and psychological well-being (see chapter 7 and chapter 8).

2.11 Summary

Illness cognition research has developed from a self-regulatory approach to understanding health-related behaviour (Leventhal et al., 1980; Leventhal et al., 1984; Leventhal et al., 1997). The cognitive representation of illness has been described in terms of (i) illness prototypes (Bishop & Converse, 1986; Bishop et al., 1987), (ii) illness schemata (Lacroix, 1991; Lacroix et al., 1991), and (iii) refinement and application of the self-regulatory model (Petrie & Weinman, 1997; Weinman et al., 1996). This latter work has emphasised the perspective of the patient and the significance of different aspects of illness representation for patients' health-related behaviour. These different components of illness representation have been termed the Identity, Cause, Time-Line, Consequences and Cure/Control components (Lau & Hartman, 1983; Leventhal et al., 1980). The same five components occur in the discourse about illness of adults (Bishop et al., 1987; Lau & Hartman, 1983; Weinman et al., 1996) and children (Goldman et al., 1991). Developmental research has implicated age and experience as determinants of the development of different components of illness representation (Paterson et al., 1999; Rosenthal et al., 1995; Schmidt & Weishaupt, 1990). Further research is needed to clarify (i) the salience of different components of illness representation in different contexts and with respect to different illnesses, and (ii) the mechanism whereby illness representations develop.

Chapter 3 Childhood Asthma

3.1 Introduction

Having presented a discussion of how cognitive developmental and experiential factors are implicated in children's understanding of illness (chapter 1), and the nature and implications of illness cognition (chapter 2), different aspects of childhood asthma and their implications for the cognitive representation of asthma will be presented and discussed.

3.2 Childhood Asthma and the Identity Component of its Cognitive Representation

Research suggests that Identity (disease label, signs and symptoms) may be a central component of the illness representation of children with asthma (Bishop et al., 1987; Campbell, 1975; Goldman et al., 1991; Lau & Hartman, 1983; Lau et al., 1989). However, little is known about the aspects of childhood asthma that may determine the Identity beliefs of patients. It is likely that illness characteristics, for example, prevalence and severity of the disease,[1] and patient

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[1] Although prevalence does not feature in the traditional illness cognition literature, the extent to which a disease is commonplace or rare may have implications for other asthma-related beliefs such as perceived consequences and health outcome. For example, during the interviews for the studies reported in chapter 7 and chapter 8, several comments suggested that in addition to disease label and symptoms, prevalence or the ordinariness of a disease was a notable aspect of Identity for some respondents: "... friends and family have asthma. So not the only one ... Just a lot more common than it used to be. So I suppose it's just a fact of life" (mother of 11-year-old with well-controlled asthma); "I've grown up with asthma in the family. Always used to having it around. Never seemed anything unusual" (parents of 11-year-old with very well controlled asthma); "Just one of those things. Children of this age group seem to have" (parents of 12-year-old with well-controlled asthma); "... friends haven't got asthma. They couldn't help me" (12-year-old with moderately well-controlled asthma); "One of very few

characteristics e.g., symptom perception and state/trait anxiety, may both influence the Identity beliefs of children with asthma and their parents.

Asthma is perhaps one of the most common chronic diseases of childhood, affecting between 4-6% of children sufficiently for them to require regular medical supervision (Central Health Monitoring Unit, 1995; Eiser, 1990a; Peckham & Butler, 1978). That is to say, of the 3.4 million people in the UK who have asthma over 1.3 million are children (National Asthma Campaign, 1997). The disease itself is an inflammatory disease (Scadding & O'Connor, 1998) characterised by bronchial hypersensitivity (Morrison, 1998).

Considerable variability exists in the severity of asthma between patients, and between discrete illness episodes for any given patient (Moss et al., 1996; Taitel et al., 1998). Renne and Creer (1985) suggested that patients acquire different expectations about asthma as a function of the severity of their attacks and given the intermittent and variable nature of asthma, patients may report different signs and symptoms depending on whether they are in a symptomatic or asymptomatic phase of the disease, or are experiencing an acute exacerbation of asthma or asthma attack (Hyland et al., 1993). Some of the signs and symptoms that can occur in connection with acute exacerbations are affective in nature (e.g., worry and fright) while others are somatic (e.g., difficulty in breathing and coughing) (Kinsman, Dahlem, Spector & Staudenmayer, 1977; Kinsman, Luparello,

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in school [with asthma]" (11-year-old with well-controlled asthma); "Also quite hard 'cos not everyone, not many people have it in my school" (11-year-old with very well-controlled asthma); "Loads of people with asthma. Most of my friends have it" (12-year-old with well-controlled asthma).

O'Banion & Spector, 1973). The four main symptoms of asthma are wheeze, breathlessness, cough and chest tightness (Ayres, 1999).

Assessments of patient morbidity have mainly focused on several different somatic aspects of asthma, including breathlessness, wheeze, cough and night-waking (Jones, Charlton, Middleton, Preece & Hill, 1992; White, Pharoah, Anderson & Freeling, 1989), although specific symptom factors identified through interviews with patients include affective as well as somatic components e.g., panic-fear, irritability, hyperventilation-hypocapnia, bronchoconstriction and fatigue (Kinsman et al., 1973), breathlessness (White et al., 1989), shortness of breath on exercise (Sibbald, 1989), wheeze (Sibbald, 1989; White et al., 1989), cough (White et al. 1989), night-waking (Gibson et al., 1995; White et al., 1989) and nocturnal attacks (Gibson et al., 1995; Sibbald, 1989). Affective aspects of asthma are considered in greater detail in the discussion of the potential consequences of asthma (see page 73).[2]

Adolescents with asthma have been reported to have poor knowledge about the main symptoms of asthma (Gibson et al., 1995). Similarly, parents attending a paediatric casualty department (77/109 of whom reported having a family member with asthma) had poor knowledge about diagnostic features and indicators of attack severity (Finn & Rickard, 1996). However, although the majority of respondents were unable to identify correctly that loudness of

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[2] The traditional illness cognition literature considers affective correlates of a disease to be part of the Identity component of disease representation. However, while it may be useful to consider the strength of Identity in terms of the number of symptoms and signs associated with a disease, affective aspects of a disease e.g., anxiety, and symptom correlates e.g., night-waking, may have greater validity as an aspect of the Consequences component of illness representation.

breathing was independent of severity of attacks, in comparison with those who had no family history of asthma, respondents with a family history of asthma were significantly more likely to identify correctly the irrelevance of breath sounds to an assessment of attack severity.[3]

3.2.1 Symptom Awareness and the Implications of Beliefs about Identity for Asthma Management

Awareness and labelling of symptoms may vary between individuals (see chapter 5), as might the extent to which perceived symptoms reflect objective measures of lung function. Fritz et al. (1996) examined the perceptions of respiratory symptoms of children with asthma with respect to objective measurements of lung function. Their findings suggested a wide range of perceptual ability within the sample. Greater accuracy of symptom perception (in terms of its consistency with objective measures of peripheral small airways function - forced expiratory flow in the mid-portion of a breath rather than peak expiratory flow rate) was associated with intelligence, and in terms of outcome, with fewer days missed from school and fewer medical emergencies. Age, age at diagnosis, total anxiety, internalising problems and externalising problems were independent of perceptual accuracy. These findings suggest that in addition to beliefs about Identity, the

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[3] This latter finding is consistent with the previous research of Fitzclarence and Henry (1990) who reported that in comparison with 'low knowledge' parents (parents who reported no contact with asthma were deemed to have low knowledge about asthma), parents with 'high knowledge' (parents of children with asthma deemed by their child's paediatrician to have good knowledge about their child's disease) were significantly more likely to recognise the independence of chest sounds to an assessment of asthma severity.

extent to which perceived signs and symptoms are consistent with objective measures of disease may have implications for some health outcome measures.[4]

Fritz et al. (1996) emphasised the significance of an individual's ability to accurately identify symptoms and respiratory distress for effective self-management. Two aspects of symptom perception were considered particularly relevant. First, for children and adolescents who are beginning to take personal responsibility for self-management of their asthma, perceptual accuracy is likely to be of particular significance in the initial stages of assuming personal responsibility for disease management. Accurate perceptions of the early signs of an acute exacerbation allow a child to take appropriate action (reductions in activity level, alterations to the environment, or the initiation of appropriate pharmacological treatment) in order to minimise or prevent further exacerbation. This is likely to be associated with on-going effective self-management, perception of disease controllability and enhanced self-esteem. These in turn are likely to be associated with greater co-operation with treatment regimens, maintenance of health behaviour and improved quality of life.

Second, accurate symptom perception is likely to lead to appropriate medical treatment decisions. In the same way that some patients may misattribute symptoms of anxiety to a physical disease (Clark, 1989), some patients may misattribute symptoms of anxiety to asthma. Park, Sawyer and Glaun (1996) described how, in some instances, there may be a discrepancy between subjective

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[4] It is a shortcoming of the studies reported in chapter 7 and chapter 8 that no objective data was collected concerning lung function. It would be of value to determine the strength of association between Identity beliefs and an objective measure of lung function.

perceptions of asthma severity and objective measures of lung function. This may be due to the presence of a co-morbid anxiety disorder associated with children's developing awareness of their own mortality. Park et al. (1996) suggested that children with asthma who have a co-morbid anxiety disorder might misattribute the physiological manifestation of anxiety to an exacerbation of asthma. Perception of symptoms in the context of such misattribution may lead to the child's recurrent, acute presentation in medical settings and attempts to control asthma with an increasing dose of medication. These ideas are consistent with the findings of other researchers who reported an association between high panic-fear predisposition and more frequent and longer hospitalisations, a higher step of treatment to control asthma, and more unnecessary use of reliever medication (Dirks, Jones & Kinsman, 1977; Dirks, Kinsman, Horton, Fross & Jones, 1978). Hyland et al. (1993) also suggested that steroid prescribing decisions may to some extent be predicted by patients' reports of their emotional reactions during exacerbations of asthma, and in particular, by their level of panic-fear.

Anxiety may also be implicated in shaping patients' beliefs. For example, although medication for the control of asthma may be effective in preventing an exacerbation of asthma, Wamboldt and Wamboldt (1996) referred to how it is unlikely to have a direct effect on symptoms of anxiety. Anxious patients may therefore report more symptoms and believe that their medication provided only limited relief. These patients may express a belief that asthma is an uncontrollable disease and consequently may be less adherent with treatment regimens, and less confident about health care professionals' and their own ability to manage asthma. In contrast, less anxious patients, may be less likely to misattribute normal physiological sensations to asthma and by virtue of their reduced state of anxious arousal, may cope more effectively with asthma-related situations. These patients may be more likely to appropriately use medication to control the signs and symptoms of asthma, and because that medication is effective for the majority of patients, they are likely to perceive asthma as a controllable disease.

3.3 Childhood Asthma and the Time-Line Component of its Cognitive Representation

Asthma is a chronic disease and although it can be controlled (Ryan, 1998), as yet there is no cure (Lane, 1996). Eighty to ninety percent of children with asthma experience their first asthmatic symptoms before the age of 4-5 years (Sly, 2000). In terms of illness episodes, Taitel et al. (1998) emphasised that asthma occurs in a context of intermittence, variability and reversibility (responds to relief medication).

For many patients, the difficulties associated with asthma may reduce over time, whereas for others, asthma-related difficulties constitute a life-long burden on quality of life (Moss et al., 1996). Although approximately 40% of children with asthma are likely to grow out of their asthma, recurrence in later life remains a threat (Lane, 1996).

Eiser et al. (1988) reported that in their study of children with asthma, although just under one fifth of children thought they would always have asthma, the majority thought they would outgrow asthma at some point in their lives. This is consistent with the finding that children with asthma and their parents generally believe that the child's asthma will improve in time (Khampalikit, 1983). However, expression of these beliefs may also represent a form of adaptive optimism. In comparison with a control group of parents who reported no experience with asthma, parents of children with asthma were less likely to express a chronic Time-Line belief (Spykerboer, Donnelly & Thong, 1986). Recent research has suggested that patients themselves may be quite uncertain about the time-line of their condition (Haughney, Barnes & Partridge, 2001; Paterson & Britten, 2000).

3.4 Childhood Asthma and the Cause Component of its Cognitive Representation

The interdependence of genetic, physiological and emotional factors in the aetiology of asthma has received considerable support in the literature (e.g., Fritz & Wamboldt, 1998; Lane, 1996). Genetic research suggests that asthma as a disease only occurs in those with a genetic susceptibility and that the disease is expressed following exposure to an environmental trigger (Morrison, 1998). To date, several environmental triggers have been identified, including dust, house dust mite, cigarette smoke, viral tract infections, particular weather conditions, and atmospheric pollution (Gibson et al., 1995; Lane, 1996; Morrison, 1998). Emotions and stress may also serve as triggers (Ayres, 1999; Kotses, 1998; Sandberg et al., 2000).

Sandberg et al's (2000) 18-month, prospective study involved children with asthma severity ranging from mild-to-moderate to severe (Step 3, 4 and 5 of the British Thoracic Society asthma management steps; The British Guidelines on Asthma Management, 1997). Child-recorded, twice daily peak flow readings and weekly symptom diaries were reviewed by a respiratory consultant at least every 3 months. Chronic and acute psychosocial stressors (at baseline, after 9 months and after 18 months) were assessed using a reliable and valid interview-based instrument. Variables associated with significantly increased risk of acute exacerbations included female sex, parental smoking, Autumn and Winter seasons, severe asthma (Step 5 of the asthma management steps) and previous asthma attacks in the past six months. Perhaps the most interesting finding however was the link between acute exacerbations of asthma and experience of stress.

Sandberg et al. (2000) reported that in the 3-6 weeks following a serious negative life event, there was a significant increase in the likelihood of an acute exacerbation of asthma, after which the level of risk returned to the pre-event level. This was not the whole story though. When a serious acute stressful event occurred against a background of chronic stress (for example, poverty, poor housing, parental physical infirmity, parental psychiatric illness, parental alcohol dependence, family discord, school problems), the likelihood of an acute exacerbation of asthma significantly increased in the two weeks immediately following the acute event. The increased risk in these circumstances was however of short duration with no increased risk associated with the 3-6-week period after the event. The authors explained these findings concerning stress and exacerbations of asthma in terms of the effects of stress on immunological functioning. Specifically, it was argued that increased stress is associated with a susceptibility to viral infections and that viral infections are associated with exacerbations of asthma.

Mattsson (1975) described an "interactional open systems model of asthma" in which the initial predisposition of a child towards asthma is affected by a variety of physical and psychological aetiological factors. Through mediating mechanisms, such as coping behaviour or physiological systems, these can lead to an exacerbation of asthma that may then impact upon the family situation. An exacerbation of asthma may influence parenting behaviour, acceptance of the ill child and family adjustment. According to Mattsson, this model explicitly conceptualises asthma as a vulnerability and an illness, and specifically, an illness that has the potential to set up a self-perpetuating cycle of precipitating factors.

Eiser et al. (1988) reported that over half of a group of children with asthma said they did not know what caused asthma. Those who did give explanations referred to heredity, allergies and/or physiological explanations. Causal factors that have been identified by parents include air pollution, heredity and allergy (Spykerboer at al., 1986).

Parents and children with asthma have identified several potential triggers of asthma. These include change in the weather, dust, worry, pollen, diet, allergy, infections, cigarette smoke, pollution, stressful situations and excitement (Eiser et al., 1988; Fitzclarence & Henry, 1990; Paterson & Britten, 2000; Spykerboer et al., 1986). Eiser et al. (1988) reported that agreement between mothers and their children as to the causes of an exacerbation of asthma was moderately good; between 61.7% and 80.9% were in agreement that dust, exercise, pollen, laughter, food and animals or birds were potential triggers.

3.5 Childhood Asthma and the Consequences Component of its Cognitive Representation

The IPQ assessment of the consequences of a disease is concerned with patients' perceptions of the seriousness of consequences. For example, "My child's asthma is a serious condition"; "Having asthma is having a serious illness"; "My child's asthma has had major consequences on their life"; "My asthma has not had much effect on things I can do". Although this provides a useful measure of the extent to which patients perceive an impact of asthma on their life, it provides little information about the specific areas of a patient's life that may be affected by their experience of illness, or how patients respond to that experience. For example, in a study of children with asthma, not being able to breathe and nocturnal attacks were the aspects of asthma that children disliked most, and in comparison with younger children, older children were more likely to dislike missing school (Eiser et al., 1988). These qualitative aspects of illness experience are also likely to influence patients' perceptions of the consequences of a disease.

This section of the chapter will identify and discuss the different ways in which chronic childhood illness and childhood asthma may impact upon the lives of children and their families and influence perception of the seriousness of the illness. There are three main conclusions to be drawn: (i) children with asthma, as a group, do not differ from physically healthy children in terms of their psychological well-being and psychosocial adjustment, (ii) children with severe asthma may be at risk of suffering from psychological disturbance, and (iii) children's self- and other-reported psychological well-being is determined by a variety of factors that include illness characteristics, child and family responses to illness, context of assessment and respondent source.

3.5.1 Consequences of Chronic Childhood Disease

In summary of the literature concerning chronic childhood illness, there is little consensus with respect to its consequences. Some authors have reported an association between disease severity and psychological disturbance (e.g., Graham, Rutter, Yule & Pless, 1967; McNichol, Williams, Allan & McAndrew, 1973; Peckham & Butler, 1978; Wamboldt et al., 1998) whereas others have reported that children's psychological difficulties were independent of disease severity (e.g., Kashani et al., 1988; Nassau & Drotar, 1995; Norrish et al., 1977; Wamboldt et al., 1998). In this respect however, other factors, for example, respondent source, may have some bearing on the extent to which psychological disturbance was reported. Furthermore, some authors who have reported no association between children's psychological difficulties and disease severity have reported an association with disease control (e.g., Norrish et al., 1977).

3.5.2 Consequences of Childhood Asthma

In comparative studies that involved children with asthma and a control group, the same discrepant findings have emerged; some authors reported no between group differences on measures of anxiety, social acceptance and social adjustment (e.g. Kashani et al., 1988; Nassau & Drotar, 1995; Peckham & Butler, 1978; Wamboldt et al., 1998) whereas others report fewer internalising and externalising problems, and less isolation among control group children (e.g., Cadman, Boyle, Szatmari & Offord, 1987; Kashani et al., 1988; Peckham & Butler, 1978). Bender and Klinnert (1998) concluded that children with asthma, as a group, did not differ from healthy control group children or normative samples on measures of psychological adjustment, and that the proportion of a sample with mild, moderate or severe asthma may explain the discrepant findings reported in the literature. Consistent with this conclusion, a recent meta-analysis concluded that although disease severity was associated with psychological disturbance, children with mild asthma are unlikely to experience psychological difficulties (McQuaid, Kopel & Nassau, 2001).

3.5.3 Patients' Experience of Asthma

Patients' experience of asthma may be conceptualised as the consequences associated with the acute aspects of the disease, for example, feelings of panic and fear during an asthma attack, and the consequences associated with the chronic aspects of the disease, for example quality of life deficits associated with the avoidance of situations likely to provoke an attack (Hyland et al., 1993; Mattson, 1975).

3.5.4 Acute Aspects of Asthma

During acute attacks of asthma patients may experience feelings of anxiety, panic, fear, irritability and fatigue, as well as being aware of a difficulty in breathing (Hyland et al., 1993; Snadden & Brown, 1992; Taitel et al., 1998). Mattsson (1975) also suggested emotional contingencies, including anxiety, sadness and fear of suffocation. As part of a questionnaire survey into the extent to which primary school children with asthma receive adequate and appropriate physical education in schools, Griffiths (2000) asked ten children about their attitudes towards physical education and physical activities. When asked how they feel when short of breath, half of the children reported that they start to panic and feel worried.

3.5.5. Chronic Aspects of Asthma

Between attacks, patients with asthma may suffer from a variety of quality of life deficits associated with the avoidance of situations likely to provoke attacks (Gibson et al., 1995; Hyland et al., 1993), as well as the discomfort and functional consequences of chronic airways inflammation (Hyland et al., 1993). In addition to the effects of asthma on school, work and leisure activities, specific quality of life deficits associated with asthma include the burden of prophylactic treatment (Hyland, 1998) and interference with family life (Osman et al., 1993). Hyland

(1998) referred to the trade-off between potential activity interference and avoidance of activity, and between the burden of treatment and the experience of symptoms.

3.5.6 Emotional Aspects of Children's Response to Asthma

Emotional responses of children to illness include fear, anger, anxiety, withdrawal and depression (Bibace & Walsh, 1981; Drotar, 1993). Depression and anxiety have also been associated with asthma (Taitel et al., 1998; Wamboldt & Wamboldt, 1996).[5] Patients have reported anxiety about when to seek medical advice (Nocon & Booth, 1991) and about asthma getting worse with age (Osman et al., 1993). Other emotional consequences that may be associated with asthma include feelings of anger or guilt, initial uncertainty about how to manage asthma, worry about possible future attacks, embarrassment about the use of inhalers in public, and worry about the long-term impact of asthma in terms of lifestyle and well-being (Gibson et al., 1995; Nocon & Booth, 1991).

Quality of life research has emphasised and confirmed many of these emotional consequences of asthma, as well as young asthma sufferers' concern with the effects of asthma on social relationships, leisure activities and school attendance (e.g., French et al., 1994; Hyland, 1998; Hyland et al., 1993). In contrast, although 31.6% of a sample of adolescents with a history of asthma reported

[5] Although associations between childhood asthma, childhood anxiety and childhood depression have been reported in the literature, Bender and Klinnert (1998) suggested that in some instances, the reported associations may be explained in terms of adult respondents' expectations concerning asthmatic children's difficulties, or in terms of the adult respondents' own emotional state.

feelings of frustration because of asthma, or concern about having asthma, 42% of the sample reported no undue frustration, concern or fear (Gibson et al., 1995). Similarly, on a self-report measure of anxiety, children with mild to severe asthma did not differ significantly from a control group of physically healthy children (Markson & Fiese, 2000).

3.5.7 Social Aspects of Children's Response to Asthma

Although problematic social adaptation to school, peers or family may be associated with chronic illness (Drotar, 1993), overall, concerning the impact of asthma on children's social adjustment, findings have been mixed. Nocon and Booth (1991) reported that the lives of patients with asthma were affected in varying ways including employment, schooling, physical activities, social interaction and personal relationships. Cadman et al. (1987) found that in comparison with a healthy control group, social isolation was slightly more prevalent in children and adolescents with chronic conditions (including asthma), although this finding was specific to the children with an associated disability. Eiser, Havermans, Pancer and Eiser (1992) reported that parents of children with asthma perceive their child to have particular difficulties with peer relations. In contrast, in a comparative study of children with and without a history of asthma, Peckham and Butler (1978) reported no differences in the children's social adjustment. Tavormina et al. (1976) reported no significant differences between test norms and the test scores of children with asthma on several dimensions of psychosocial functioning, including social desirability, neuroticism, extraversion, locus of control, conformity, dependence, maturity, aggression, activity level, sleep disturbance, alienation and expression. Graetz and Shute (1995) reported that in comparison with healthy classmates, children with asthma were perceived as less healthy and missing more school, but their peer relationships were equivalent to those of their healthy peers; there were no significant differences between the children with asthma and the physically healthy children on measures of popularity, reciprocated friendships, rejection, self-perceived loneliness, social reputation for sociability-leadership, social reputation for aggressive-disruptive, social reputation for sensitive-isolation, and perceived sporting ability. Similarly, Nassau and Drotar (1995) reported no significant differences in the social competence (social adjustment, social performance and social skills) of children with IDDM, children with asthma, and physically healthy children who had no history of chronic illness.

Nassau and Drotar (1995) speculated that the children with IDDM and the children with asthma experienced minimal disruption to their peer relationships (neither group of children were absent from school more often than physically healthy children) and that IDDM and asthma are less stigmatising than other visually recognisable medical conditions. They also speculated about the presence of protective factors and whether children with social difficulties were likely to participate in the research. Perhaps most importantly, Nassau and Drotar referred to the time-line of an illness and suggested that peer relationship difficulties may be more problematic at diagnosis, rather than after a period of time in which the children have learned to manage illness-related demands in a social context. Furthermore, for 8-10-year-olds, perceptions of being different and consequent social difficulties may be less evident than among adolescents, where peer group influences and perceptions are of greater salience (Boice, 1998). Parents of the children with a chronic disease may also have taken specific actions, such as educating others about their child's condition, to ensure that their child participated fully in social activities. In this respect, the aforementioned social aspects of chronic illness have been suggested to be the potential consequences of a disease that affects children's ability to participate in normal, age-appropriate activities (Nassau & Drotar, 1995; Tavormina et al., 1976). Tavormina et al. suggested that the mediating mechanisms were the child's perceptions of being different from their peers and inappropriate parental attitudes and behaviour. Nassau and Drotar suggested that children with chronic physical conditions might suffer from disruption to peer relationships for several reasons, including limitations on the type and extent of contact with peers. It was suggested that such effects may be determined by the restrictions that a disease places on physical activities, parents' perceptions of the need to protect their child, and the perceived stigma associated with a disease.

Zbikowski and Cohen (1998) also referred to the potential consequences of parental overprotection with contingent reduced opportunities for interaction with peers, and to levels of self-esteem and coping strategies that may be associated with social withdrawal, internalising problems that may lead to reduced motivation to interact with peers despite having adequate social skills, and developmental changes in the nature of children's friendships. Together, these experiences may constantly challenge or threaten normal developmental processes (Eiser et al., 1992). As children's self-concept develops in a social context (Miell, 1995), influences of asthma on the behaviour of others may lead to a change in the child's behaviour, primarily through the mechanism of effecting change in the child's self-perceptions.

Other reactions within a family to chronic childhood illness may also influence a child's perceptions and responses and alter family dynamics (Bleil, Ramesh, Miller & Wood, 2000; Drotar, 1993; Eiser et al., 1992; Maes, Leventhal & De Ridder, 1996; Osman, 1998; Shapiro, 1983). For example, meaningful family rituals were negatively associated with the self-reported anxiety of children with mild to severe asthma (Markson & Fiese, 2000). Positive maternal behaviour and paternal involvement in child management and asthma care were associated with a child's social behaviour and self-sufficiency (Renne & Creer, 1985). Shared concern and interest in the well-being of family members and appropriate provision of emotional support were negatively associated with children's self-reported distress about their asthma and its consequences (Sawyer, Spurrier, Kennedy & Martin, 2001). Concordance in beliefs about the best way to manage a child's illness may improve adherence with treatment recommendations (Fiese & Wamboldt, 2000).

Family interactions may also be associated with children's social competence. For example, family discussion of internal states may facilitate a child's social competence through the encouragement of perspective-taking, improvements in emotional understanding, and the development of a shared language to describe internal states (Dunn & Brown, 1994; Wilkinson, 1988). Eiser et al. (1992) suggested that different expectations and perceptions within a family system may serve the function of achieving a balance between protecting the child from the consequences of a disease and providing them with age-appropriate opportunities for normal development. This view is consistent with Burton's (1975) suggestion that good adjustment to chronic disease was likely to be found in those families where a balance was reached between protection of the child and the provision of opportunities for normal development.

3.5.8 Determinants of Children's Other- and Self-Reported Psychological Well-Being

Discrepancies in the research concerning the consequences of chronic illness, may be explained in four ways: (i) illness severity, (ii) protective health-related behaviour, (iii) context of assessment, and (iv) source of information.

3.5.9 Illness Severity as a Determinant of Children's Other- and Self-Reported Psychological Well-Being

Tavormina et al.'s (1976) respondents had a range of illness severity, although the 'modal' respondent was reported to have a mild form of an illness. Mattsson (1975) provided no data about illness severity, duration or participant recruitment and simply referred to what any individual child with asthma and their family may experience. It may be that the respondents who reported the psychosocial difficulties described in Mattsson's (1975) discussion were patients with more severe forms of illness, or patients for whom there were additional complicating factors to which Tavormina et al.'s (1976) participants were not exposed. That severity of illness was a significant factor in explaining the discrepancy between

Tavormina et al.'s (1976) findings and those reported elsewhere (e.g., Mattsson, 1975) is suggested by the findings of Norrish et al. (1977).

Norrish et al. (1977) carried out a comprehensive assessment of clinical, physiological and psychological aspects of asthma in a group of sixty-three 8-15-year-olds. Severity of asthma was reported in terms of the type of regularly prescribed medication over the previous six months and was specified as mild, moderate or severe. Physiological measures included peak flow measurements and the results of an exercise test to assess bronchial lability. Psychological measures included parents' and teachers' reports of the children's health and behaviour, and a child personality questionnaire to assess emotionality and extraversion. Although severity of asthma and reports of emotional and/or behavioural difficulties were not correlated, control of asthma was significantly negatively associated with the children's other-reported emotional and/or behavioural difficulties.

Nocon and Booth (1991) reported an association between disease severity and the impact of asthma on social adjustment. Participants were adult patients with asthma and the parents of children with asthma. All the patients had been admitted to hospital with a primary diagnosis of asthma one year prior to the start of the study. It was suggested that because this group was likely to include patients with severe asthma, the study would be able to draw firm conclusions about the potential impact of asthma on the social adjustment of patients and their families.

Nocon and Booth (1991) graded asthma severity in terms of the severity of physical symptoms. The categories used to grade illness severity were based on descriptions provided by the patients. Examination of these categories suggests that what the patients actually reported was their perceived control of symptoms. That type of medication taken to control asthma, a potential indicator of disease severity, has been independent of children's social competence (Nassau & Drotar, 1995), is consistent with the suggestion that in comparison with disease severity, perception of disease control may be a better predictor of children's psychological well-being. In comparison with physically healthy children and other children with asthma, Graetz and Shute (1995) reported that children with more hospitalisations were less preferred as playmates, were perceived as more sensitive-isolated and felt lonelier.

More recent studies have also considered severity and control of asthma and children's psychological well-being. Wamboldt et al. (1998) investigated the relationship between severity of asthma and children's psychological difficulties. The participants in Wamboldt et al.'s study were medical in-patients and children who attended an asthma camp. Asthma severity was physician-determined on the basis of medical records that included information about pre-treatment daytime symptoms, nocturnal symptoms and objective measures of lung function. Clinical evidence of non-adherence documented in the medical histories was taken into account when reaching a decision about severity. Although children's anxiety scores were independent of disease severity or markers of functional morbidity, and were not significantly different from standardised norms, parents' reports of their child's internalising problems were associated with disease severity and also with the parents' tendency to report their own physical symptoms. These findings further suggest that perceived severity of asthma and perceptions concerning the control of asthma may be distal antecedents of other more proximal factors, which mediate the relationship between illness characteristics and the reported psychosocial consequences of asthma. Specifically, it is suggested that concordance in the beliefs of parents and their child about an illness, including its consequences, and the correlates of belief concordance, mediate the relationship between illness characteristics and psychological well-being. This is the main thesis of the studies reported in chapter 7 and chapter 8.

3.5.10 Engagement in Protective Behaviour as a Determinant of Children's Other- and Self-Reported Psychological Well-Being

Mattsson (1972) suggested that the risk of psychosocial problems might be minimised through encouraging self-responsibility and open discussion of illness; the children who participated in the Tavormina et al. (1976) study may have been children who, through encouragement, assumed self-responsibility and engaged in open discussion about illness. Extending the thesis outlined above, it may be that discussion about asthma promotes belief concordance that reduces family conflict concerning disease-related situations. This reduced level of family conflict may be associated with the child's perception of family support and understanding and their parent- and self-reported positive adjustment.

3.5.11 Context of Assessment as a Determinant of Children's Other- and Self-Reported Psychological Well-Being

McQuaid et al. (2001) concluded that on the basis of a meta-analysis of studies that have reported global functioning assessment data, in comparison with their healthy peers, children with asthma were at risk of suffering from adjustment difficulties. However, it was reported that findings were less consistent when instruments assessed anxiety and depression specifically. The test battery used by Tavormina et al. (1976) focused on general psychosocial functioning, whereas Mattsson (1975) emphasised specific emotional consequences associated with chronic illness and its management. It is likely that illness-specific instruments and procedures are required for an accurate assessment of the psychosocial consequences of chronic illness (Juniper, 1998). In comparison with generic instruments, disease-specific instruments enquire about specific aspects of an illness that are likely to concern patients and their families (Rutishauser, Sawyer & Bowes, 1998). Similarly, child-centred approaches are indicated for the assessment of paediatric patients' quality of life (Christie & French, 1994; Christie, French, Sowden & West, 1993). Recent research suggests that to enquire of patients as to their specific illness representations and experience of illness yields a consistently more useful understanding of the way in which chronic illness impacts upon their daily routine (e.g., Hyland et al., 1995; Petrie & Weinman, 1997).

Similarly, the operationalisation of related constructs within a domain may determine research outcome. For example, in considering parent and peer evaluations of the social competence of 6-12-year-old children with mild asthma, Zbikowski and Cohen (1998) reported that in comparison with older children with asthma and physically healthy children, young children with asthma had lower social competence based on their parents' reports and fewer close friends based on both their parents' and peers' reports. However, physically healthy children and children with asthma did not differ on peer measures of popularity or social acceptance.

3.5.12 Source of Information as a Determinant of Children's Other- and Self-Reported Psychological Well-Being

Zbikowski and Cohen's (1998) findings also suggest that the source of information may determine both the nature and the extent of children's other- and self-reported difficulties. Norrish et al. (1977) reported that scores from parents' reports indicated more emotional than behavioural problems among children identified as having difficulties, whereas teachers' reports indicated an equal prevalence of behavioural and emotional problems. For children identified as having problems on the basis of parents' and teachers' reports, there was low agreement as to whether the children's problems were emotional, behavioural or mixed. In contrast to the findings of Norrish et al., interviews and test batteries that have involved child respondents suggest that children report fewer difficulties (e.g., Tavormina, et al., 1976).

Kashani et al. (1988) also recognised that parents' reports of the psychological well-being of their child with asthma may differ from the children's self-reports, and that although severity of asthma indexed on the basis of medication requirements may be an appropriate index of disease severity, correlating well with physiological measures, control of asthma may be of greater relevance to the psychological aspects of the disease.

Kashani et al. assessed the psychological well-being of 56 children with asthma who were consecutive attenders at a University Child Health Clinic. All were referred with a diagnosis of asthma classed as mild, moderate or severe according to medication requirements. The control group were children with no chronic illness who were attending the same clinic for other medical reasons, including acute respiratory infections, gastrointestinal problems, ear, nose and throat problems, minor injuries or accidents and immunisation. A structured psychiatric interview for children and adolescents (Herjanic, Herjanic, Brown & Wheatt, 1975; Herjanic & Reich, 1982) suggested no significant differences between the groups on psychiatric symptom reports and no correlation between asthma severity and psychiatric diagnosis on the basis of the interview assessment.[6]

However, a parent-version of the interview suggested that in comparison with the control group, the children with asthma had a greater number of psychiatric symptoms, specifically of the over-anxious and phobic kind. Assessment with a child behaviour checklist suggested that, in comparison with the control group parents, the parents of the children with asthma reported that their child had more internalising and externalising behaviour, although control group parents and

[6] Bussing, Burket and Kelleher (1996) expressed concern about the high rate of psychological disturbance in both the control and asthma group that was reported by Kashani et al. (1988). They suggested the possibility of patient selection effects and questioned the validity of Kashani et al.'s measurements.

parents of children with asthma did not differ significantly in their assessment of their child's social competence.

Kashani et al. (1988) suggested that parents of children with asthma were more likely to report psychopathology in their children than were the children with asthma, or the parents of children with medical conditions other than chronic illness. The value of multiple informants has been emphasised in the recent literature (e.g., Klinnert, McQuaid, McCormick, Adinoff & Bryant, 2000; McQuaid et al., 2001).

3.5.13 Consequences of Childhood Asthma for Parents

Parents of children with asthma may experience restrictions in their daily activities, as well as emotional stresses, because of their child having asthma (Townsend, Feeny, Guyatt, Furlong, Seip & Dolovich, 1991). These may include concerns and worries about their child's diagnosis and the course of their child's condition, the long-term effects and side-effects of asthma medication, the policy of their child's school concerning inhalers and the impact of the child's asthma on other relationships within the family (Donnelly et al., 1987; Paterson & Britten, 2000; Staudenmayer, 1981; Townsend et al., 1991). However, these reports should be viewed in the context that for many parents of children with pre-diagnosed asthma, a diagnosis of asthma brings parents' experiences of frustration, helplessness and fear to an end (Horner, 1997). For some families, childhood asthma may be associated with family cohesion, children's pro-social behaviour and parental coping with other situations (Donnelly et al., 1987).

3.6 Childhood Asthma and the Cure/Control Component of its Cognitive Representation

Cure/Control was reported to be the aspect of asthma about which 13-14-year-old students and their teachers were most knowledgeable (Gibson et al., 1995). However, only 71% of adolescents with asthma referred to a bronchodilator (medication to provide symptomatic relief) when asked about useful treatments during an acute attack. Of perhaps greater concern was the finding that only 1% of adolescents with asthma were able to identify correctly how to prevent exercise-induced asthma (for example, by taking a relief inhaler about 15 minutes before exercise and use of a warm-up period; Ayres, 1999) and only 3.5% were able to identify two preventative treatments taken daily (e.g., inhaled steroids, cromoglycate, nedocromil, leukotriene blockers; Ayres, 1999; Fitzclarence & Henry, 1990). Eiser et al. (1988) also reported poor knowledge about the control of asthma among children; although the majority of children reported using an inhaler, trying to relax and/or avoiding triggers as potential asthma management strategies, a significant minority reported that they themselves did nothing to reduce the likelihood of an asthma attack.[7]

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[7] It is worth noting several points about Eiser et al.'s (1988) design. In particular, the asthma group, made up of 38 out of 49 children (77.6%) who were regularly attending hospital clinics for treatment, may have been unrepresentative of most children with asthma. Children regularly attending a hospital for treatment of asthma are likely to have the least-well controlled asthma. Although these children's disease may have been so severe that clinical management was difficult, it is possible that the regular clinic attendance of this group of children was a consequence of poor management. Poor management may be a consequence of poor understanding. Through having a large proportion of the sample group whose severity of asthma was potentially confounded with the control of asthma, the generalisability of any conclusions is limited insofar as the sample group is primarily made up of children who are potentially those with the poorest understanding or least sophisticated representation of asthma. Eiser et al. also reported no data concerning duration of asthma or time since diagnosis; the length of time that a child has been living with asthma may well impact upon knowledge, awareness and ability to take specific action to avoid situations known to provoke an attack. There was no differentiation of atopic (allergy-

3.6.1 The Medical Perspective: Definition and Achievement of Control

Guidelines for the control of asthma, defined in terms of symptoms and function, recommend varying the type and dose of medication to achieve effective control (The British Guidelines on Asthma Management, 1997). This may involve 'stepping up' or 'stepping down' the use of short- or long-acting bronchodilators and inhaled or oral steroids (anti-inflammatory medication). Other recommendations include avoidance of precipitating factors, patient education and involvement, and selection of the best inhaler device. In terms of controllability, for the majority of patients with asthma, the disease can be well controlled with the right treatment (Ryan, 1998).

3.6.2 The Patients' Perspective: Attitudes towards Medication Use and Correlates of Cure/Control Beliefs

Jones et al. (1992) identified a subgroup of patients with asthma who reported high morbidity despite treatment with either bronchodilators or bronchodilators and steroids. The finding of high morbidity among patients prescribed inhaled steroids was suggested to possibly indicate poor compliance or poor inhaler technique, or that patients' prescribed dose of steroid may have been too low to achieve effective control, or that steroids were prescribed to patients with the most severe and difficult to control asthma (in terms of perceived symptoms). In this context, patients' attitudes toward the use of asthma medication may have been salient.

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induced) asthma from asthma of unknown cause, a differentiation that could impact upon knowledge of allergens and ability to take specific action to avoid precipitating situations.

Patients' attitudes toward regular preventative asthma management and self-medication were assessed as part of a study into adult patients' negative attitudes toward four different aspects of asthma intrusiveness: (i) physical dysfunction and disability, (ii) social and emotional interference, (iii) interference with public life, and (iv) medication (Osman et al., 1993). It was reported that although some patients disliked inhaled steroids generally, a considerable proportion of the same patients reported no dislike of their own particular inhaled steroid. In contrast, patients who disliked using their own particular inhaled steroid were also likely to express unfavourable views toward use of their own particular bronchodilator, inhaled steroids generally, and daily medication. Although it was suggested that patients' might have different attitudes toward bronchodilators and inhaled steroids (patients' were suggested to be more likely to use relief medication than preventative medication), little difference in patients' attitudes toward relief medication and preventative medication were observed.

Jensen and Karoly (1992) reported that, patients' beliefs about the effectiveness of medication in achieving control or cure of an illness were associated with their use of medications and coping strategies. Patients who believe that taking asthma medication leads to effective control of their asthma are more likely to engage in preventative health behaviour, develop a collaborative treatment alliance with health professionals, and participate in the development of individual treatment plans (Zimmerman, Bonner, Evans & Mellins, 1999). Individual treatment plans empower patients through encouraging them to make their own decisions about when to increase and decrease treatments (Hyland, 1998). Patients who take fuller responsibility for their treatment are likely to have an illness representation of asthma as a controllable disease. A belief that asthma is controllable has been suggested as a determinant of psychological adjustment (e.g., Kashani et al., 1988; Norrish et al., 1977). In adults with asthma, perceptions of control and efficacy were associated with reduced risk of hospitalisation, less frequent activity restriction, and continuation of employment (Katz, Yelin, Smith & Blanc, 1997). Janson and Reed (2000) reported that patients' perception of greater control with respect to their breathing difficulties was associated with their perception of fewer symptoms, less serious exacerbations or consequences, less disruption to normal activities, fewer emotional difficulties and improvement in quality of life.

3.7 Summary

Different aspects of childhood asthma and their potential to impact upon the cognitive representation of asthma were described. In a discussion of the factors that may be relevant to the Identity component, the implications of symptom perception were discussed. In a discussion of the factors that may be perceived as the cause of asthma, special attention was given to the influence of stress as a potential cause of exacerbation. Consequences of asthma, primarily emotional and social, as they may determine patients' perception of the seriousness of their illness, were discussed in some detail. It was concluded that although children with severe asthma may be at risk of suffering from psychological disturbance, as a group, children with asthma do not differ from other children in terms of their psychological well-being. Inconsistencies in the literature were highlighted and explained by reference to illness severity, engagement in protective behaviour e.g., family discussion, the context of assessment of psychosocial functioning i.e., the operationalisation of constructs and the appropriateness of assessment instruments, and the source of information about the child's condition. The stress of a protracted pre-diagnosis phase and medication-related worries were emphasised in a discussion of the factors that may determine the perceived seriousness of the consequences of childhood asthma for parents. The potential positive consequences associated with childhood asthma were outlined. The chapter concluded by introducing the findings of research into patients' and lay-people's knowledge about the control of asthma, an overview of the medical perspective and a discussion of the implications of patients' beliefs about, and attitudes towards, medication use.

Chapter 4 Methods

Four studies were undertaken with physically healthy children, children with asthma, and parents of children with asthma (see Table 4.1).

4.1 Aims

The first two studies (an exploratory study and a replication study) were mainly concerned with children's awareness and descriptions of respiratory sensations. The third and fourth studies focused on cognitive representations of asthma, childhood asthma sufferers' psychological well-being and reasons for achieving good control of asthma. Each study involved a series of analyses with several distinct aims.

The first aim of the initial exploratory study (see chapter 5) and the replication study (see chapter 6) was to improve our understanding of the developmental changes in children's awareness of respiratory sensations, their description of respiratory sensations and their knowledge about the respiratory system. The second aim was to improve our understanding of the role of experience and considered the same outcome variables in the context of children's experience with asthma.

Table 4.1

Overview of Study Design and Method

Study	Aim/Research	Population	Participants	Age range (years)	n	Instrument
1	Developmental changes and the role of experience in children's awareness and description of respiratory sensations and their knowledge of the respiratory system	School	Children with asthma	7 - 8	11	Awareness of respiratory sensations
				10 - 11	6	Demographic & clinical information
						Descriptions of breathing &
			Physically healthy children	7 - 8	33	knowledge of the respiratory system
				10 - 11	19	Experience of difficulty in breathing
2	Test the reliability of the findings from study 1	School	Children with asthma	7 - 8	23	Awareness of respiratory sensations
				10 - 11	25	Demographic & clinical information
			Physically healthy children	7 - 8	67	
				10 -11	72	

Table 4.1 contd.

Overview of Study Design and Method

Study	Aim/Research	Population	Participants	Age range (years)	n	Instrument
3	Nature and variability of beliefs about asthma; How children's beliefs about asthma relate to the system of beliefs within the child's family; How demographic factors and illness characteristics are associated with beliefs about asthma	School	Parents of children with asthma Children with asthma	30 - 50 10 - 11	31 31	Demographic & clinical information Illness Perception Questionnaire Semi-structured interview Sophistication of verbal representation of asthma
	Nature and extent of other- and self-reported psychological difficulties; Associations between beliefs about asthma and psychological well-being;Test the hypothesis that concordance in beliefs of parents and their child about asthma was associated with psychological well-being					Belief concordance Demographic & clinical information Illness Perception Questionnaire Strengths & Difficulties Questionnaire
	Reasons for achieving good control of asthma; Nature of asthma intrusiveness					Reasons for achieving good control of asthma

Table 4.1 contd.

Overview of Study Design and Method

Study	Aim/Research	Population	Participants	Age range (years)	n	Instrument
4	As for study 3, with disease severity as an additional independent variable		Parents of children with mild asthma[a]	29 - 46	46	Belief concordance Demographic & clinical information Disease severity
			Parents of children with severe asthma[a]	33 - 45	17	Illness Perception Questionnaire Reasons for achieving good control of asthma
		Hospital asthma database & primary care	Children with mild asthma	10 - 13	40	Semi-structured interview Sophistication of verbal representation of asthma
			Children with severe asthma	10 - 13	13	Strengths & Difficulties Questionnaire
	Test the reliability of the findings from study 3 with respect to the participants' reasons for achieving good control of asthma					Reasons for achieving good control of asthma

Table 4.1 contd.

Overview of Study Design and Method

Study	Aim/Research	Population	Participants	Age range (years)	n	Instrument
4	Test the hypothesis that disease severity, parental sensitivity to their child's internal states, and family discussion about asthma were associated with the quality of a child's description of what out of breath feels like	Hospital asthma database & primary care	Parents of children with mild asthma[a]	29 - 46	46	Awareness of respiratory sensations Demographic & clinical information Disease severity Family discussion about asthma Parental sensitivity to their child's internal state
			Parents of children with severe asthma[a]	33 - 45	17	
			Children with mild asthma	10 - 13	40	
			Children with severe asthma	10 - 13	13	

[a] Conjoint interviews were conducted with ten couples.

The third study (see chapter 7) involved three analyses:

Analysis 1 had three aims. First, the nature and variability of children's beliefs about asthma are not well understood and an important aim of the study was to improve our knowledge of these matters. This was achieved through an examination of participants' responses to a semi-structured interview and a modified version of the asthma-specific Illness Perception Questionnaire (IPQ) (Weinman et al., 1996). Second, to improve our understanding of how children's beliefs about asthma relate to the system of beliefs within the child's family, concordance in the beliefs of parents and their child about the child's asthma was assessed. Third, to improve our understanding of the associations between the physiological and the psychological aspects of asthma, associations between asthma severity and beliefs about asthma were examined.

The first aim of analysis 2 was to determine the nature, extent and impact of the children's psychological difficulties. The second aim was to examine associations between the participants' beliefs about asthma and their reports of the children's psychological well-being. The third aim was to test the hypothesis that belief concordance is associated with good psychological adjustment.

The first aim of analysis 3 was to improve our knowledge about childhood asthma sufferers' (and their parents') reasons for achieving good control of asthma. The second aim was to improve our knowledge about how asthma intruded upon the participants' daily lives. These aims were achieved by using a procedure for eliciting goals that was described by Bagozzi and Edwards (1998).

The fourth study reported in chapter 8 involved the same three analyses that were outlined for study 3 with disease severity as an additional variable. A fourth analysis returned to the theme of respiratory sensations and aimed to test the hypothesis that disease severity, parental sensitivity to their child's internal states and family discussion about asthma were associated with the quality of a child's description of what out of breath feels like.

4.2 Participant Recruitment

Participants were recruited through state schools in the Midlands (study 1 through 3), through a hospital asthma database (study 4) and through GP practices in the West Midlands (study 4). Recruitment through schools (study 1 and study 2) and health care settings (study 4) was undertaken to recruit a representative and purposeful sample of children and children with asthma respectively.[1] Details of the recruitment procedure are presented in the relevant chapters.

[1] In study 3, purposeful recruitment through schools was undertaken to recruit a representative sample of children with asthma, in part because of the complicated nature of recruitment through health care settings. In retrospect, the latter was considered to be the preferred of the two methods because of the potential influence of engaged medical practitioners and nurses in encouraging patient participation in a clinically relevant study. However, in practice, both methods suffered from low response rates (see chapter 9).

4.3 Interview Schedule and Instruments[2]

4.3.1 Demographic and Clinical Information

A parent-completed questionnaire provided demographic details, including parents' occupation, child and family history of asthma and the child's contact with anyone known to have asthma. If appropriate, parents were asked to provide details of the child's asthma medication and to rate the level of control of their child's asthma on a seven-point Likert scale ranging from very poorly-controlled to very well-controlled. Subsequent to interview in study 1, the parents of the children with asthma, and the parents of the children who used inhalers were asked to provide details of the child's asthma/respiratory difficulties.[3]

Details about a child's contact with other asthma sufferers outside of the family was excluded from the parent-completed questionnaire of study 3 and study 4, which provided further demographic details including the age of the child, parents' cohabitation status, number of children living in the household, number of cigarette smokers in the household, and details of the child's asthma. Jarman (1983; 1984) underprivileged area scores that corresponded to a family's postcode address were obtained via the local Health Authority Public Health Office.

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[2] Copies of all the questionnaires used are presented in the Appendix.

[3] In study 2, details about the children's respiratory difficulties were obtained prior to interview.

4.3.2 Disease Severity

Although an objective measure of lung function would have provided useful information about disease severity,[4] the child's Step of Treatment according to the British Guidelines on Asthma Management (1997) was used as an index of disease severity for pragmatic reasons. Step of treatment ranges from 0 (no medication is required to achieve control of symptoms) to 5 (a high dose of medication is required to achieve control of symptoms).

4.3.3 Semi-Structured Interview

Four open-ended questions explored participants' thoughts and feelings about the child's asthma: (i) "Could you tell me something about [child's name]'s/your asthma?", (ii) "How do you feel about [child's name]/having asthma?", (iii) "Is there anything about [child's name]/having asthma that is a particular concern/worry for you?", and (iv) "How would things be different for you, if [child's name]/you didn't have asthma?"

4.3.4 Awareness of Respiratory Sensations

Storyboards were designed to represent five different situations in which breathing and respiratory sensations may be salient: (i) blowing up several balloons (Balloon scenario), (ii) jumping into a swimming pool and swallowing

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[4] Treatment decisions (and therefore Step of Treatment) may be influenced by patient behaviour and reports that are independent of disease severity (Hyland et al., 1993).

some water (Swimming scenario), (iii) running for a bus (Running scenario), (iv) playing a recorder at a school concert (Recorder scenario), and (v) having a cold and recovering from having a cold (Cold/Recovery scenario) (see Figure 4.1). There were two control stimuli: (i) having a nice, hot drink after playing outside in the cold (Control Scenario 1), and (ii) being on a big wheel at a fun fair (Control Scenario 2). The order of presentation of scenarios (Control Scenario 1; Balloon; Swimming; Running; Cold/Recovery; Recorder; Control Scenario 2) was kept constant across all interviews. Participants were asked how a scenario character might feel after engaging in the scenario behaviour. Children who reported a character feeling out of breath were asked to talk in greater detail about what out of breath feels like.

4.3.5 Descriptions of Breathing and Knowledge about Respiration

Four questions explored the children's ideas about breathing in different situations: (i) "How do we breathe when we run fast?", (ii) "How do we breathe when we sit quietly?", (iii) "What is the difference between how we breathe when we run fast and how we breathe when we sit quietly?", and (iv) Why is there a difference between how we breathe when we run fast, and how we breathe when we sit quietly?". Four questions explored the children's knowledge about the respiratory system and respiration: (i) "What happens to the air after we breathe it in?", (ii) "Is the air that we breathe out the same as the air that we breathe in?", (if different) (iii) "What is different about the air that we breathe out?", and (iv) "What happens to the air that we breathe in to make the air that

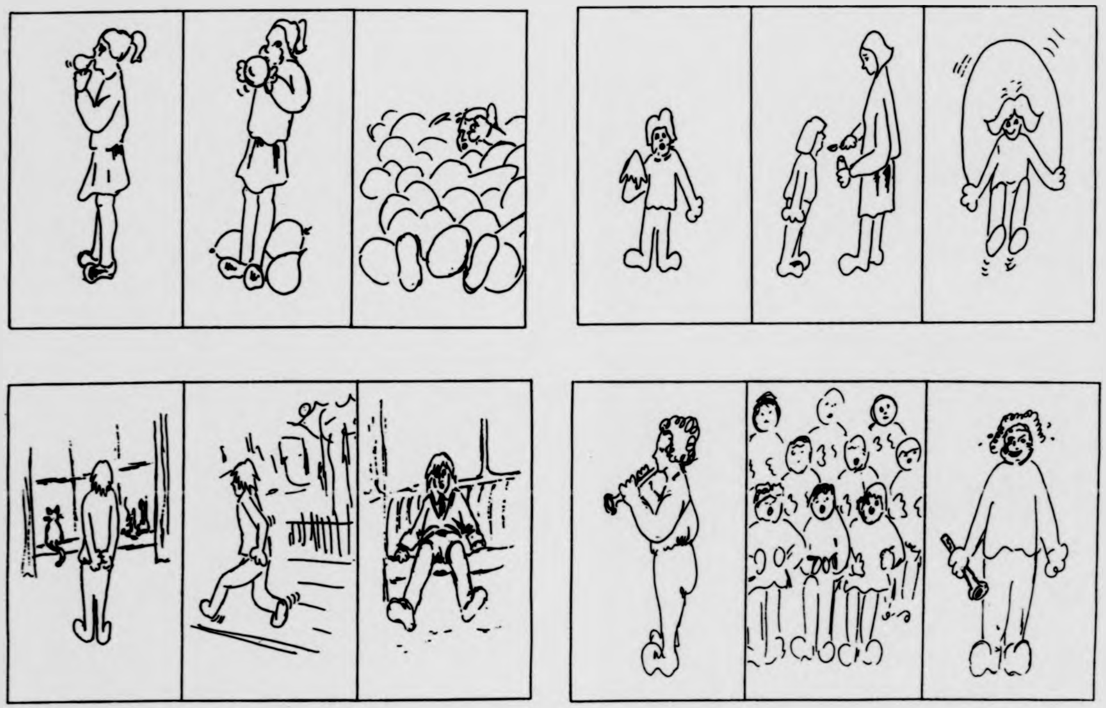

Figure 4.1 Storyboard stimuli: Balloon scenario (top left); Cold/Recovery scenario (top right); Running scenario (bottom left); Recorder scenario (bottom right)

we breathe out different?". The order of questions was kept constant and corresponded to the order presented herein.

4.3.6 Experience of Difficulty in Breathing

Three questions asked about children's experience of difficulty in breathing: (i) "Do you ever have any difficulty in breathing?", (ii) Does anyone in your family ever have difficulty in breathing?", and (iii) Do you know anyone (else) who ever has any difficulty in breathing?".

4.3.7 Illness Perception Questionnaire

The Illness Perception Questionnaire (IPQ) (Weinman et al., 1996) is a validated, theoretically derived questionnaire assessment of the cognitive representation of illness. The original asthma-specific version of the IPQ consists of 45 items, each loading on one of the five illness representation component scales: Identity (19 items), Time-Line (4 items), Cause (10 items), Consequences (7 items) and Cure/Control (5 items). The modified version of the asthma-specific IPQ (64 items) included a sixth scale (12 items) that was concerned with patients' beliefs about the causes of an exacerbation of asthma. This also contained extra Identity (3), Time-Line (1), Cause (2), Consequences (1), and Cure/Control (1) items.[5]

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[5] The extra Identity items 'Spots', 'Toothache' and 'Feeling shaky' were originally included as control items. Subsequently it was realised that a fine tremor may be a side-effect of bronchodilator use (Association of the British Pharmaceutical Industry, 1996) and experience of shakiness could be attributed to either asthma or its treatment.

The child-version of the modified questionnaire (IPQ-C) was developed by rephrasing potentially difficult to understand items and by excluding three irrelevant items (perceived economic and financial consequences of having asthma and the extent to which parents believed that they contributed to the cause/exacerbation of their child's asthma). The parent-version of the Consequences item, "My child's asthma has strongly affected the way my child sees himself/herself as a person", was replaced with three items concerned with the child's self-perceptions: (i) "My asthma has had a big effect on how I think about myself", (ii) "My asthma has had a big effect on how I feel about myself", and (iii) "I think I am different to other people because I have asthma". The instrument sub-scales and items are presented in Table 4.2- 4.7.

The Identity scale of the parent- (IPQ-P) and child-version of the modified IPQ is scored by summing the number of items endorsed as experienced occasionally, or more often. High scores indicate perception of more symptoms. The items of the remaining four scales are rated for agreement on a five-point Likert scale. Time-Line, Consequences and Cure/Control scale totals are calculated by summing constituent item ratings. For the Consequences scale of the IPQ-C, total scores were derived from the average rating for the three self-perception items referred to above added to the remaining individual item ratings. The Cause/Cause of Exacerbation items are considered individually. Internal reliabilities for each of the IPQ scales are presented in Table 4.8.

Table 4.2

Identity Scale

Parent-version	Child-version[a]
Pain	
Nausea	*Feeling sick*
Breathlessness	*Feeling out of breath*
Weight gain	*Putting on weight*
Fatigue	*Feeling tired*
Tight chest	
Panic attacks	*Suddenly feeling scared/panicky*
Headaches	*Head-aches*
Upset stomach	*Upset tummy*
Sleep difficulties	*Hard to sleep*
Nervous tension	*Feeling nervous or stressed out/find it hard to relax*
Weight loss	*Losing weight*
Spots	
Sore eyes	
Toothache	
Anxiety	*Feeling worried when you think about your asthma*
Sore throat	
Wheezing	
Hair falling out	
Dizziness	*Feeling dizzy*
Feeling shakey[b]	
Loss of strength	*Feeling weak*

[a] Child-version items that were phrased differently to the corresponding Parent-version item are presented in italics, adjacent to the Parent-version of the item. [b] Omitted from the parent-version of the questionnaire used in study 3.

Table 4.3

Cause Items

Parent-version	Child-version[a]
It was just by chance that my child got asthma	*It was just bad luck that I have asthma*
My child's asthma is largely due to my child's behaviour	*It's my fault that I have asthma*
Other people played a large role in causing my child's asthma	*It's other people's fault that I have asthma*
My child's asthma was caused by poor medical care in the past	*Doctors and nurses helped cause my asthma*
No-one is to blame for my child having asthma[c]	*It's no-one's fault that I have asthma*[c]
Stress was a major factor in causing my child's asthma in the first place	*Stress helped cause my asthma in the first place*
My child's state of mind played a major part in causing their asthma	*How I think and feel caused my asthma in the first place*
A germ or virus caused my child's asthma to begin with	*A germ or virus caused my asthma to begin with*
Diet played a major role in causing my child's asthma to begin with	*Things I ate and drank helped cause my asthma to begin with*
Pollution of the environment caused my child's asthma in the first place	*Dirty air helped cause my asthma in the first place*
My child's asthma is heredity – it runs in our family	*Asthma is something that runs in my family*

[a] Child-version items that were phrased differently to the corresponding Parent-version item are presented in italics, adjacent to the Parent-version of the item. [b] Item only included in the Parent-version of the modified asthma-specific IPQ. [c] Reverse scored item.

Table 4.4

Exacerbation Items

Parent-version	Child-version[a]
It is just by chance if my child's asthma gets worse	*Bad luck can make my asthma worse*
If my child's asthma gets worse it is largely due to my child's behaviour	*If my asthma gets worse it is my own fault*
If my child's asthma gets worse it is other people's fault	*If my asthma gets worse it is other people's fault*
If my child's asthma gets worse it is the doctors' and nurses' fault	*If my asthma gets worse it is the doctors' and nurses' fault*
It's no-one's fault if my child's asthma gets worse[c]	*It's no-one's fault if my asthma gets worse*[c]
Stress can make my child's asthma worse	*Stress can make my asthma worse*
My child's state of mind can make their asthma worse	*How I think and feel can make my asthma worse*
My child's diet can make their asthma worse	*Things I eat and drink can make my asthma worse*
Pollution of the environment can make my child's asthma worse	*Dirty air can make my asthma worse*
Being near cats, or dogs, or other animals can make my child's asthma worse	*Being near cats, or dogs, or other animals can make my asthma worse*
Cigarette smoke can make my child's asthma worse	*Cigarette smoke can make my asthma worse*

[a] Child-version items that were phrased differently to the corresponding Parent-version item are presented in italics, adjacent to the Parent-version of the item.

[b] Item only included in the Parent-version of the modified asthma-specific IPQ. [c] Reverse scored item.

Table 4.5

Time-Line Scale

Parent-version	Child-version[a]
My child will have asthma for only a short time[b]	*I won't have asthma when I'm a bit older*[b]
My child will always have asthma	*I will always have asthma*
My child's asthma will improve in time[c]	*My asthma will eventually get better*[c]
My child's asthma is likely to be permanent rather than temporary[c]	
My child will have asthma for a long time[c]	*When I'm grown up I won't have asthma*[b, c]
	When I'm old I won't have asthma[b, c]

[a] Child-version items that were phrased differently to the corresponding Parent-version item are presented in italics, adjacent to the Parent-version of the item. [b] Reverse scored item. [c] Item excluded from scale total calculation.

Table 4.6

Consequences Scale

Parent-version	Child-version[a]
My child's asthma is a serious condition	*My asthma is a serious illness*
Having a child with asthma is having a child with a serious medical condition[b]	*Having asthma is having a serious illness*[b]
My child's asthma has had major consequences on their life	*My asthma has had big effects on things I can do*
My child's asthma has become easier for my child to live with[c]	*It isn't that bad having asthma*[c]
My child's asthma has not had much effect on their life[c]	*My asthma has not had much effect on things I can do*[c]
My child's asthma has strongly affected the way others see my child	*People think I'm different because I have asthma*
My child's asthma has serious economic and financial consequences[b, d]	
My child's asthma has strongly affected the way my child sees himself/herself as a person	*My asthma has had a big effect on how I think about myself*[e]
	My asthma has had a big effect on how I feel about myself[e]
	I think I am different to other people because I have asthma[e]

[a] Child-version items that were phrased differently to the corresponding Parent-version item are presented in italics, adjacent to the Parent-version of the item. [b] Item excluded from scale total calculation. [c] Reverse scored item. [d] Item only included in the Parent-version of the modified asthma-specific IPQ. [e] The average of the score on these items was used when the Consequences scale total was calculated.

Table 4.7

Cure/Control Scale

Parent-version	Child-version[a]
My child's state of mind can make their asthma better[b]	*How I think and feel can make my asthma better*[b]
There is a lot that my child can do to control their symptoms	*There is a lot that I can do to make my asthma better*
There is very little that can be done to improve my child's asthma[c]	*Nothing much can help make my asthma better*[c]
My child's treatment is effective in controlling their asthma[b]	*My asthma medicine makes my asthma better*[b]
My child's treatment will be effective in curing their asthma[b]	*My asthma medicine will cure my asthma*[b]
My child's recovery from their asthma is largely dependent on chance or fate[b, c]	*It will just be good luck if I ever get better*[b, c]
What my child does can determine whether their asthma gets better or worse[b]	*Things I do can make my asthma better or worse*[b]

[a] Child-version items that were phrased differently to the corresponding Parent-version item are presented in italics, adjacent to the Parent-version of the item. [b] Item excluded from scale total calculation. [c] Reverse scored item.

Table 4.8

Internal Reliability of the Modified, Asthma-Specific IPQ

	Study 3	
	Internal reliability (Cronbach's alpha)	
IPQ scale	IPQ Parent-version	IPQ Child-version
Identity	0.78	0.79
Time-Line	0.81	0.60
Consequences	0.63	0.68
Cure/Control	0.62	0.68

	Study 4	
	Internal reliability (Cronbach's alpha)	
IPQ scale	IPQ Parent-version	IPQ Child-version
Identity	0.74	0.80
Time-Line	0.85	0.85
Consequences	0.65	0.81
Cure/Control	0.64	0.40

4.3.8 Sophistication of the Participants' Verbal Representation of Asthma

The sophistication of the participants' verbal representation of asthma was operationalised as the number of illness representation components that were represented in their response to the question, "Could you tell me something about [child's name]'s/your asthma?"

4.3.9 Belief Concordance

Belief concordance was calculated for each parent-child pairing by allocating a score of one for each IPQ item on which the parents and their child each expressed agreement/disagreement or uncertainty.[6] [7] For each of the IPQ scales a belief concordance score was calculated by summing the score for the constituent items.

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[6] Concordance might have been operationalised by subtracting the score allocated to a child's response to an IPQ item from the score allocated to their parent's response to the equivalent item. This method would have facilitated an analysis of the nature of discordance, for example, when beliefs about the seriousness of a child's asthma were discordant, was there a tendency for the parents or their child to express stronger agreement/disagreement. However, the magnitude of the difference between agreement/disagreement response options in the real world, for example, "strongly agree" and "agree", may not be equivalent to that between agreement/disagreement and uncertainty i.e., "neither agree nor disagree". Also, the focus of the analysis was belief concordance.

[7] Concordance between the beliefs of the parents and their child concerning the 'Self-Perceptions' consequences of the child's asthma was determined by assessing concordance between the parents' rating of the child's self-perception and the average rating for the three IPQ-C self-perception items.

4.3.10 Family Discussion about Asthma

Family discussion about asthma was operationalised as concordance in the beliefs of the parents and their child about asthma. Belief concordance total scores were calculated by summing the IPQ item concordance scores.

4.3.11 Parental Sensitivity to Their Child's Internal States

Parental sensitivity to their child's internal states was operationalised as concordance between the beliefs of the parents and their child concerning the signs and symptoms (Identity) of the child's asthma. Identity concordance scores were calculated by summing the concordance scores from IPQ Identity scale items.

4.3.12 Strengths and Difficulties Questionnaire

The parent- (P4-16) and child- (S11-16) versions of the Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997; 1999; Goodman, Meltzer & Bailey, 1998) are brief, child behaviour screening questionnaires that measure 25 different positive and negative attributes. The five sub-scales measure conduct problems, emotional symptoms, hyperactivity, peer relationships and prosocial behaviour over the last six months (Goodman, 1997). Each sub-scale is made up of five items rated on a three-point scale. With the exception of Prosocial Behaviour sub-scale score, where a low score indicates a poor psychosocial adjustment, high total scores on the remaining sub-scales (which can be summed to generate a Total Difficulties score) indicate more difficulties. The extended version of the SDQ (Goodman, 1999) was used, that includes an impact supplement. This explored perceived difficulties in the areas of emotions, concentration, behaviour or being able to get on with other people, with sub-questions concerning aspects such as chronicity and degree of burden to others. Four response options are provided for each sub-question and these were scored with the "0012" scoring system (Goodman, 1999). The total Impact score is calculated by summing the sub-question scores. The Impact score of respondents who report no difficulties in response to the initial impact supplement question is zero. In the present study, caseness was defined as a score within the abnormal range (Goodman, 1997; Goodman et al., 1998).

4.3.13 Reasons for Achieving Good Control of Asthma

The participants were asked to identify five reasons for achieving good control of asthma/getting asthma under control, and to say why each reason was important. As a guided example (study 3 only),[8] participants were asked to think about reasons for achieving the health goal of eating healthy food and avoiding unhealthy food. Specific reasons provided as examples included, "to stay healthy", and "to grow properly". "To live longer", and " because I enjoy living" were cited as examples of important reasons to stay healthy. "So I can do what I want to do", and "because that makes me happy" were cited as examples of important reasons to grow properly.

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[8] The procedure was modified for the fourth study because provision of a worked-through example may have served to prompt the participants.

4.4 Procedures

In all studies the procedure involved semi-structured interviews with the study participants.[9] Questionnaires were either self-completed by the participants (study 3) or completed on their behalf by the interviewer at the participant's request (study 3) or with their permission (study 4).[10] Details of the procedures are presented in the relevant chapters.

4.5 Data Analysis

Data analysis involved both qualitative (content analysis involving application of a pre-defined coding framework and inductive content analysis) and quantitative (chi-square tests or their exact probability equivalents, correlations, sign tests, t-tests, analysis of variance, simple and multiple regression analysis) methods to address the distinct aims of each analysis outlined above and in Table 4.1.

[9] Rather than send out postal questionnaires that would have reduced interview duration and may have improved response rates, it was decided that questionnaires should be completed during interviews to minimise missing data and to ensure that children completed the questionnaires without the assistance of their parents. The latter was particularly important in the studies that focused on belief concordance.

[10] This modification to the procedure in study 4 was undertaken to control for differences in reading abilities within the sample and consequent variation in the duration of the questionnaire phase of the interview.

Chapter 5

Study 1

5.1 Introduction

The literature described in chapter 1 suggests that there may be significant associations between children's age, their experience of asthma and their knowledge of biological concepts. Although age has been consistently associated with improved knowledge of biological concepts, inconsistent findings have been reported concerning the effects of experience with a chronic illness. For example, Eiser et al. (1988) reported that, in comparison with a group of healthy children, a group of children with asthma were less well informed about general knowledge of the body. Eiser et al. (1993) reported that relevant experience led to improved ability to recall new biological information. From an applied perspective, the ability of children to detect and describe changes in their respiratory system has implications for asthma management (Fritz et al., 1996; Fritz & Wamboldt, 1998). Although Skevington, Pilaar, Routh and MacLeod (1997) have described how breathless patients describe breathlessness, little is known about how children with asthma or physically healthy children talk about respiratory sensations.

The first aim of study 1 was to improve our understanding of the developmental changes in children's awareness of respiratory sensations, their description of respiratory sensations and their knowledge of the respiratory system. The second aim was to improve our understanding of the role of experience, by considering the same outcome variables in the context of children's experience with asthma. The study also considers how children acquire the language that they use to describe respiratory sensations.

Formal knowledge of breathing and the respiratory system were assessed through simple factual questions framed within an age-appropriate context. In addition, a series of scenarios (Figure 4.1) was presented to 7-8- and 10-11-year-olds, who were asked to imagine being the scenario character and to describe what they would feel in each situation e.g., after blowing up several balloons or after running for a bus. This procedure enabled an assessment of the extent to which children of different ages were differentially aware of, or focused on, respiratory sensations and respiratory distress, and the extent to which children of different ages were able to describe respiratory sensations. Through an analysis of children's responses to the scenarios, and knowing the child's personal history with respect to asthma, it was possible to determine the relevance of personal experience for the development of respiratory awareness and the development of language for the description of respiratory sensations.

5.2 Method

5.2.1 Participants

Two primary schools in the Midlands were asked to distribute project information packs to the parents/guardians of all children in Year 3 (7-8-year-olds) and Year

6 (10-11-year-olds). Parents who were willing to allow their child to participate were asked to return a completed consent form to the child's school.

5.2.2 Instruments

The study instruments (Awareness of respiratory sensations; Demographic and clinical information; Descriptions of breathing and knowledge of the respiratory system; Experience of difficulty in breathing) are described in chapter 4.

5.2.3 Procedure

Demographic details and information about a child's asthma were collected in advance of interview. All children were asked to give verbal assent at the time of interview. Individual interviews lasted between 20 and 30 minutes. The interviews were conducted at the child's school. Participants were presented with the storyboard scenarios and asked how a character might feel after engaging in the scenario behaviour. Children who reported a character feeling out of breath were asked to talk in greater detail about what out of breath feels like. The participants were then asked a series of questions about breathing, the respiratory system and respiration. Finally, the participants were asked about their own and others' experience of difficulty in breathing. Participants' responses were audio recorded and transcribed. Subsequent to interview, the parents of the children with asthma and the parents of the children who used inhalers were asked to provide details of their child's asthma/respiratory difficulties.

5.2.4 Data Analysis

The children's descriptions of how a character might feel in different everyday situations were subjected to an inductive content analysis. This allowed a consideration of differences (i) between the reports of older and younger children, (ii) within each age group, between the reports of boys and girls, and (iii) within each age group, between the reports of children with and without a history of asthma. Analysis of the data focused on breathing awareness in the context of the different situations, and the children's descriptions of what out of breath feels like. Similarly, an inductive content analysis of the children's responses to the questions about breathing, the respiratory system and respiration was undertaken.

Each response category within each scenario was scored 0 (response category absent) or 1 (response category present) based on an analysis of each child's interview transcript. The same dichotomous scoring of response categories was applied to the children's description of what out of breath feels like, and their talk about breathing and respiration. Reports concerning the transformation of air were scored 0 (no transformation), 1 (unspecified transformation), or 2 (specific transformation).

Cochran's chi-square test compared the likelihood that different scenarios were likely to elicit different responses. Chi-square was used to test for significant associations between the children's responses for each scenario and their age, sex and medical history with respect to asthma. Analysis of variance of the total score calculated for each response category (the number of scenarios in which a response category was represented) tested for main effects and interactions of age-group, sex and history of asthma. Chi-square was also used to test for significant associations between the study variables and the children's descriptions of breathlessness and knowledge of the respiratory system. Where appropriate, the values of the chi-square statistic reported incorporated Yate's correction for continuity.

5.3 Results

Parental consent was given for 69 children, 44 from Year 3 and 25 from Year 6, a response rate of about 50%. Interviews were conducted with 29 boys (42%) and 40 girls (58%). Seventeen (24.6%), forty-eight (69.6%), and forty-four (63.8%) children had a history of asthma, a family history of asthma, and were friends with someone who had asthma respectively. Five children (7.2%) had no experience with asthma. Of the 17 children with asthma, 15 (88.2%) were taking asthma medication.

5.3.1 Awareness of Respiratory Sensations

Content analysis generated five main response categories: (i) "Out of Breath", (ii) "Tiredness", (iii) "Hotness or Sweating", (iv) "Breathing", and (v) "Emotion". A sixth response category, "Wheeze", was introduced following the content analysis of the data from study 2. Definitions of the response categories are presented in Table 5.1. Two independent raters coded a random selection of thirty-five

Table 5.1

Categories of Attributions Elicited by Storyboard Stimuli

Attribution category	Definition
Breathing	Reference to how someone might breathe. For example, if the child demonstrated how someone might breathe after blowing up several balloons or talked about any dimension of breathing such as rate or depth
Emotion	Report of a scenario character feeling a specific emotion
Hotness/Sweating	Report of a scenario character feeling hot/sweaty, or sweating
Out of Breath	Report of a scenario character feeling out of breath, breathless, puffed out, needing to get air, experiencing a lack of air or any similar phrase
Tiredness	Report of a scenario character feeling tired, worn out, exhausted or any similar phrase
Wheeze	Reference to wheeze

interview transcripts. Cohen's kappa coefficients were all between 0.83 and 1.0.[1] Disagreements were discussed and whenever possible resolved. Total scores for each response category were calculated for each participant by summing the number of scenarios that elicited the response category.

The results of Cochran's test indicated that different scenarios elicited different responses from the children (Table 5.2).[2] The Balloon, Running and Recorder scenarios were particularly likely to elicit attributions of breathlessness. In contrast, the Cold and Recovery scenarios were unlikely to elicit such attributions ($\chi 2(4) = 138$, $p < 0.001$). All scenarios were reasonably unlikely to elicit descriptions of breathing or attributions of wheeze ($\chi 2(4) = 5.2$, ns and $\chi 2(4) = 4.0$, ns respectively).

There were no significant associations between the reports of children from different schools, or between the reports of the boys and the girls.

5.3.2 Awareness of Respiratory Sensations: Associations with Age

In comparison with the younger children, the older children were significantly more likely to make attributions of breathlessness in response to the Balloon (χ^2 (1) = 5.00, $p < 0.05$), Running (χ^2 (1) = 4.23, $p < 0.05$) and Recorder (χ^2 (1) = 10.48, $p < 0.005$) scenarios. Analysis of variance of the Out of Breath Total

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[1] Wheeze was not included as a response category when the initial reliability analysis was undertaken.

[2] The Control and Swimming scenarios elicited very few attributions of respiratory sensations. Data derived from these scenarios were excluded from further analysis.

Table 5.2

Number of Children who made Specific Attributions in Response to Storyboard Stimuli ($N = 69$)

	Scenario					
Attribution category	Balloon	Running	Recorder	Cold	Recovery	Cochran's χ^2
Out of breath	48(69.6)	37 (53.6)	36 (52.2)	2 (2.9)	0 (0.0)	138****
Tiredness	49 (71.0)	53 (76.8)	35 (50.7)	10 (14.5)	0 (0.0)	134****
Emotion	4 (5.8)	9 (13.0)	34 (49.3)	26 (37.7)	54(78.3)	105****
Hotness/Sweating	12(17.4)	11 (15.9)	16 (23.2)	2 (2.9)	0 (0.0)	31****
Breathing	1 (1.4)	5 (7.2)	7 (10.1)	6 (8.7)	5 (7.2)	5
Wheeze	0 (0.0)	0 (0.0)	0 (0.0)	1 (1.4)	0 (0.0)	4

Note. Percentages are presented in parentheses.

**** $p < 0.001$

Score by age group, sex and history of asthma also indicated a main effect of age (F (1, 61) = 10.9, $p < 0.005$).

5.3.3 Awareness of Respiratory Sensations: Associations with Asthma

The children's attributions in response to the storyboard stimuli were not correlated with their experience of asthma.

5.3.4 Awareness of Respiratory Sensations: Higher Order Interactions

There was a significant 3-way interaction for Emotion Total Score by age-group, sex and history of asthma (F (1, 61) = 6.38, $p < 0.05$) (Table 5.3). In comparison with the physically healthy, younger boys, the physically healthy, older boys reported emotion less often, and in comparison with the physically healthy, younger girls, the physically healthy, older girls reported emotion more often. This pattern was reversed for the children with asthma; in comparison with the younger boys, the older boys reported emotion more often, and in comparison with the younger girls, the older girls reported emotion less often.

5.3.5 Descriptions of What Out of Breath Feels Like

Content analysis generated eight main response categories: (i) "Internal, Respiratory Sensations", (ii) "Hotness or Sweating", (iii) "Action of Breathing", (iv) "Difficulty in Breathing", (v) "Sore Throat", (vi) "Tiredness", (vii) "Cough", and (viii) "Wheeze". Definitions of the response categories are presented in Table

Table 5.3

Number of Scenarios that Elicited Attributions of Emotion by Age and History of Asthma

	7-8-year-olds					
	Mean number scenarios		Standard deviation		Sample size	
Group	Boys	Girls	Boys	Girls	Boys	Girls
Physically healthy	2.21	1.84	1.25	1.21	14	19
Asthma	1.75	2.57	0.96	1.13	4	7
	10-11-year-olds					
	Mean number scenarios		Standard deviation		Sample size	
Group	Boys	Girls	Boys	Girls	Boys	Girls
Physically healthy	0.75	2.27	0.89	1.62	8	11
Asthma	2.67	1.67	0.58	1.53	3	3

5.4. Two independent raters coded a random selection of thirty-five interview transcripts. Cohen's kappa coefficients were all between 0.84 and 1.0. Any disagreements were discussed and whenever possible resolved.

In response to the scenario stimuli, 51 children (73.9%) made attributions of breathlessness. Out of breath was often described as tiredness (37.3% of sample), or in terms of how someone might breathe when they were out of breath (31.4% of sample). Six children (11.8%) provided more detailed descriptions of what out of breath feels like. Five of these children had a history of asthma. The sixth was physically healthy and reported no experience with asthma. Although 47 children (68.1%) had some degree of contact with someone known to have asthma, only one of these children was able to provide a reasonably detailed description of what out of breath feels like.

5.3.6 Descriptions of What Out of Breath Feels Like: Associations with Age

Detailed descriptions of what out of breath feels like were significantly associated with age ($\chi 2(1) = 4.27$, Fisher's exact, $\underline{p} < 0.05$) (Table 5.5), although four of the six older children who provided the detailed descriptions were also children with a history of asthma. A description of how someone might breathe (when asked what out of breath feels like) was also significantly associated with age ($\chi 2(1) = 7.79$, $\underline{p} < 0.01$).

Table 5.4

Descriptions of Breathlessness

Description category	Definition
Action of breathing	Description of how someone might breathe when breathless. For example, breathing deeply, breathing fast
Cough	Reference to cough
Internal sensation	Description of subjective, internal sensations. For example, throat feels cold
Difficulty in breathing	Reference to a difficulty in breathing. For example, hard to breathe or can't breathe very well
Hotness/Sweating	Reference to hotness or sweating
Tiredness	Reference to tiredness
Sore throat	Reference to a sore throat
Wheeze	Reference to wheeze

Table 5.5

Number of Breathlessness Description Categories by Age

Description category	7-8-year-olds[a]	10-11-year-olds[b]
Action of breathing	5 (11.4)	11 (44.0)**
Cough	0 (0.0)	2 (8.0)
Internal sensation	1 (2.3)	5 (20.0)*
Difficulty in breathing	2 (4.5)	4 (16.0)
Hotness/Sweating	2 (4.5)	2 (8.0)
Tiredness	10 (22.7)	10 (40.0)
Sore throat	0 (0.0)	2 (8.0)
Wheeze	0 (0.0)	0 (0.0)

Note. Percentages are presented in parentheses.

[a] $n = 44$. [b] $n = 25$.

* $p < 0.05$, ** $p < 0.01$

5.3.7 Descriptions of What Out of Breath Feels Like: Associations with Asthma

The older children's detailed description of what out of breath feels like was significantly associated with their experience of asthma ($\chi 2(1) = 7.25$, Fisher's exact, $p < 0.01$) (Table 5.6), as was their description of out of breath as a difficulty in breathing ($\chi 2(1) = 3.87$, Fisher's exact, $p < 0.05$).

The detailed descriptions of what out of breath feels like provided by the five children with asthma invariably contained a report of a subjective, internal sensation. For example, "... I can't breathe very well, I can't breathe in and out. It's like I've got something in my back of my throat and there's only a little bit left, to get air in by" (11-year-old boy with a history of asthma poorly-controlled with medication), "... it's like my chest is getting tighter and like my lungs are crushing in" (11-year-old boy with a history of asthma well-controlled with medication).

An 11-year-old girl with no experience of asthma also referred to a subjective, internal sensation when asked to describe what out of breath feels like: "throat goes sore ... tummy starts hurting". However, the sensations described were qualitatively different to those described by the children with asthma, who referred to the action of breathing and to sensations located within the respiratory system.

Table 5.6

Number of Breathlessness Description Categories by Age and History of Asthma

Description category	7-8-year-olds: Physically healthy[a]	7-8-year-olds: Asthma[b]
Action of breathing	4 (12.1)	1 (9.1)
Cough	0 (0.0)	0 (0.0)
Internal sensation	0 (0.0)	1 (9.1)
Difficulty in breathing	1 (3.0)	1 (9.1)
Hotness/Sweating	0 (0.0)	2 (18.2)
Tiredness	9 (27.3)	1 (9.1)
Sore throat	0 (0.0)	0 (0.0)
Wheeze	0 (0.0)	0 (0.0)

Description category	10-11-year-olds: Physically healthy[c]	10-11-year-olds: Asthma[d]
Action of breathing	10 (52.6)	1 (16.7)
Cough	1 (5.3)	1 (16.7)
Internal sensation	1 (5.3)	4 (66.7)**
Difficulty in breathing	1 (5.3)	3 (50.0)*
Hotness/Sweating	2 (10.5)	0 (0.0)
Tiredness	8 (42.1)	2 (33.3)
Sore throat	2 (10.5)	0 (0.0)
Wheeze	0 (0.0)	0 (0.0)

Note. Percentages are presented in parentheses.

[a] n = 33. [b] n = 11. [c] n = 19. [d] n = 6.

* $p < 0.05$, ** $p < 0.01$

5.3.8 Descriptions of Breathing and Knowledge about Respiration

Content analysis generated ten response categories: (i) "Depth", (ii) “Rate”, (iii) “Sound”, (iv) “External", (v) "External-Internal", (vi) "Energy", (vii) "Physiological Systems", (viii) "No Transformation", (ix) "Unspecified Transformation", and (x) "Specific Transformation". Definitions of the response categories are presented in Table 5.7. Two independent raters coded a random selection of thirty-five interview transcripts. Cohen's kappa coefficients were all between 0.80 and 1.0. Any disagreements were discussed and whenever possible resolved.

As a group, the children’s descriptions of breathing focused on external features e.g., “you breathe out your mouth” (62.3% of sample), the rate of breathing (62.3% of sample), and the link between the external and internal environments e.g., “the pipe from your nostrils goes into your lungs” (72.5% of sample). Twenty-four children (34.8%), seventeen children (24.6%) and twenty-eight children (40.6%) reported no difference, an unspecified difference, and a specific difference between the air that is breathed out and the air that is breathed in. Although only two children (2.9%) gave a reasonably comprehensive, biological account of respiration, twenty children (29.0%) made a link between breathing and another physiological system, mainly the cardiovascular system.

Table 5.7

Descriptions of Breathing and Respiration

Description category	Definition
External description	External description of breathing. For example, you breathe out your mouth
External-internal link	Reference to a link between the external and internal environments. For example, the pipe from your nostrils goes into your lungs
Energy	Reference to energy
Link with other physiological systems	Reference to a link between breathing, respiration or the respiratory system and other physiological systems
Rate	Reference to the rate of breathing
Sound	Reference to the sound of breathing
No transformation	Report of there being no difference between the air that is breathed in and the air that is breathed out
Unspecified transformation	Report of an unspecified difference between the air that is breathed in and the air that is breathed out
Specific transformation	Report of a specific difference between the air that is breathed in and the air that is breathed out

5.3.9 Descriptions of Breathing and Knowledge about Respiration: Associations with Age

Children's descriptions of breathing and their knowledge about the respiratory system were significantly associated with age (Table 5.8); in comparison with younger children, the older children were more likely to make a link between the external and internal environments ($\chi 2(1) = 6.04$, $p < 0.01$) and to make a link with other physiological systems ($\chi 2(1) = 23.4$, $p < 0.001$). When asked about the difference between the air that is breathed out and the air that is breathed in, in comparison with older children, the younger children were more likely to report no difference ($\chi 2(1) = 7.46$, $p < 0.01$), or an unspecified difference ($\chi 2(1) = 7.33$, $p < 0.01$). In comparison with younger children, the older children were more likely to report a specific transformation ($\chi 2(1) = 27.9$, $p < 0.001$). Of the seven younger children (15.9%) who were able to report a specific transformation of the air that is breathed in, all had a family history of asthma or were friends with children who had asthma. Of the three older children (12.0%) who reported no difference between the air that is breathed in and the air that is breathed out, none had a history of asthma.

5.3.10 Descriptions of Breathing and Knowledge about Respiration: Associations with Asthma

The older children's reference to energy when they talked about breathing was significantly associated with their experience of asthma ($\chi 2(1) = 3.1$, Fisher's exact, $p < 0.05$) (Table 5.9).

Table 5.8

Number of Breathing and Respiration Description Categories by Age

Description category	7-8-year-olds[a]	10-11-year-olds[b]
Energy	4 (9.1)	2 (8.0)
External description	30 (68.2)	13 (52.0)
External internal link	27 (61.4)	23 (92.0)**
Link with other systems	4 (9.1)	16 (64.0)****
Rate	26 (59.1)	17 (68.0)
Sound	12 (27.3)	2 (8.0)
No transformation	21 (47.7)	3 (12.0)***
Unspecified transformation	16 (36.4)	1 (4.0)***
Specific transformation	7 (15.9)	21 (84.0)****

Note. Percentages are presented in parentheses.

[a] n = 44. [b] n = 25.

** $p < 0.01$, *** $p < 0.005$, **** $p < 0.001$

Table 5.9

Number of Breathing and Respiration Description Categories by Age and History of Asthma

	7-8-year-olds	
Description category	Physically healthy[a]	Asthma[b]
Energy	3 (9.1)	1 (9.1)
External description	24 (72.7)	6 (54.5)
External-internal link	20 (60.6)	7 (63.6)
Link with other systems	4 (12.1)	0 (0.0)
Rate	20 (60.6)	6 (54.5)
Sound	8 (24.2)	4 (36.4)
No transformation	15 (45.5)	6 (54.5)
Unspecified transformation	11 (33.3)	5 (45.4)
Specific transformation	7 (21.2)	0 (0.0)

	10-12-year-olds	
Description category	Physically healthy[c]	Asthma[d]
Energy	0 (0.0)	2 (33.3)*
External description	9 (47.4)	4 (66.7)
External-internal link	17 (89.5)	6 (100.0)
Link with other systems	12 (63.2)	4 (66.7)
Rate	12 (63.2)	5 (83.3)
Sound	2 (10.5)	0 (0.0)
No transformation	3 (15.8)	0 (0.0)
Unspecified transformation	1 (5.3)	0 (0.0)
Specific transformation	15 (78.9)	6 (100.0)

Note. Percentages are presented in parentheses.

[a] n = 33. [b] n = 11. [c] n = 19. [d] n = 6.

* $p < 0.05$

5.4 Discussion

The study has demonstrated a significant association between a child's age and their attributions of breathlessness. Age and experience of asthma were significantly associated with the quality of the children's descriptions of what out of breath feels like. This is consistent with cognitive-developmental (Crider, 1981) and functionalist (Eiser, 1989; Eiser et al., 1993; Paterson et al., 1999) perspectives on children's development of illness concepts. A child's age was associated with their knowledge of respiratory physiology. This is consistent with other studies (e.g., Clarke & Newell, 1997; Gellert, 1962; Perrin et al., 1991).

High levels of variability in the variance between each group of interest and small expected frequencies in some of the chi-square cells suggest caution when interpreting the results. There were also concerns about artefactual responses. For example, the social context of a school concert (Recorder scenario) and the visual representation of an overtly happy child skipping (Cold/Recovery scenario) may have elicited reports of a socially constructed emotion and an intra-personal emotion respectively, rather than reports of a physiological state or sensation.

In comparison with the older children, the younger children were less likely to report a character feeling out of breath after blowing up several balloons and after playing a recorder. It has been suggested that younger children are guided by the external characteristics of a situation (Neuhauser et al., 1978), whereas older children attend to underlying principles (Rosenthal et al., 1995). For these reasons, in comparison with the older children, the younger children may have been less likely to associate breathlessness with the static activity of blowing up balloons. In situations where external activity is visible, for example when running, it is likely that these age differences would disappear. The results supported this hypothesis. In contrast, older children know that sensations ordinarily associated with physical exertion may be elicited by other behaviour in some instances. This has implications for how the respiratory sensations associated with asthma are explained to younger children. Given that there were no significant associations between a child's attributions of physiological sensations and the child's experience of asthma, these associations with age may be particularly important.

An alternative explanation concerns the labelling of respiratory sensations. Although older and younger children may be equally aware of the sensations associated with various activities, in comparison with younger children, older children may have a greater vocabulary with which to describe those sensations. Furthermore, there may be a distinction between the labelling of sensations, a linguistic competence, and the awareness, or recognition, of sensations, a perceptual competence. In comparison with younger children, older children may be more adept at both recognition and labelling tasks, and for this reason, are able to locate discrete, physical sensations in particular regions of the body. In contrast, either because younger children are unable to perceptually differentiate discrete sensations, or because they lack the vocabulary to differentiate discrete sensations in their discourse, younger children may use non-specific descriptors e.g., tiredness, to describe different sensations.[3]

These findings are consistent with reports that, in comparison with younger children, older children are more able to differentiate internal organs and integrate physiological systems (Crider, 1981; Yoos, 1994). In the present study, developmental changes in children's knowledge of respiration and the respiratory system lend further support to this suggestion and are consistent with the findings of Clarke and Newell (1997), who reported an association between a child's age and their knowledge about the lungs.

Although education is likely to be a significant determinant of developmental differences in biological knowledge (Au et al., 1999),[4] other factors may determine the benefit that a child derives from formal education and the likelihood that, at any given age, they are able to perceive and describe accurately their subjective, internal states. For example, although all the older children had received a comparable level of formal education about respiratory physiology, some were unable or unwilling to talk about a specific transformation of air within the body. These children had little or no experience with asthma. In contrast, the

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[3] In comparison with older children, younger children may have less experience with blowing up balloons or playing the recorder. For this reason, the younger children may be less likely to project feelings of breathlessness. However, experience in playing the recorder was not significantly correlated with any of the response category dimensions. There was insufficient data to draw any conclusions about experience in blowing up balloons as an explanation of age group differences, although it is plausible that, in comparison with older children, younger children had less experience in blowing up balloons.

[4] In Year 6 of primary school, 10-11-year-olds are introduced to the internal body and learn about the structure and function of internal body parts (Clarke & Newell, 1997).

younger children who referred to a specific transformation of air within the body were likely to have had experience with asthma. Similarly, in terms of age, all the older children were equally likely to have experienced sensations contingent on physical exertion yet few provided a detailed description of what out of breath feels like. The children who provided a detailed description of what out of breath feels like were all children who had experience with asthma.

Eiser et al. (1993) suggested that experience provides a framework that facilitates understanding. For this reason, children with asthma may provide detailed descriptions of respiratory sensations and demonstrate a good understanding of respiratory physiology. It has been suggested that there is an association between a child's age and their differentiation and localisation of internal, respiratory sensations. Experience with asthma may provide an additional opportunity for children to develop sophisticated representations of their respiratory concepts. For example, with age, 'out of breath', as a descriptor of an internal sensation, may become differentiated from the descriptor 'tiredness', and less bound to an overt, behavioural context. Similarly, terms relating to the sensations associated with asthma may become differentiated from the descriptor 'out of breath'. This is consistent with Kalish's (1999) suggestion that experience leads to the differentiation of concepts. The findings of the present study support this hypothesis; whereas the younger children with asthma described out of breath in terms of both external behaviour and various non-specific sensations such as tiredness and hotness or sweating, the older children with asthma provided more detailed descriptions that included subjective, internal sensations.

However, while this suggestion is plausible, only 9.1% and 66.7% of the younger and older children with asthma respectively provided a detailed description of what out of breath feels like. Although the younger children may have been constrained by age, in their ability to differentiate, perceive or describe internal sensations, if experience of asthma was the determining factor, a greater proportion of the older children should have provided a detailed description of what out of breath feels like.[5] The association between the Cold and Recovery scenarios and the children's attributions of emotion suggest an explanation for this finding.

Insofar as the healthy children were concerned, with age, the girls and boys were more and less likely respectively to make attributions of emotion. The reverse was true for the children with asthma. The pattern of responses of the healthy children may be explained by the socialisation of gender role expectations (Woodhead, Barnes, Miell & Oates, 1995). Insofar as the children with asthma were concerned, illness experience is likely to be associated with negative affect. Dunn and Brown (1994) reported that, in comparison with positive affect, negative affect is more likely to elicit family discussion of emotion. While many children with asthma are likely to cope well and experience relatively little asthma-related negative affect, others' illness experience may lead to negative affect that is likely to stimulate family discussion. For the boys with asthma, family discussion of affective states that are associated with the experience of asthma may have led to an increased competence in their ability to describe and talk about internal states,

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[5] Although the data from the present study indicated that the duration of the child's diagnosis was significantly associated with their detailed description of what out of breath feels like ($r = 0.84$; $n = 6$, $p < 0.05$), this finding was not replicated in the study that followed (see chapter 6).

including internal, respiratory sensations. The direct effect of this was that the boys with asthma were more likely to make attributions of affect.

As to why the girls with asthma demonstrated the reverse of this pattern may be explained by cultural expectations concerning health and sick role behaviour. Although girls and boys with asthma may be equally competent in their perception and labelling of internal states, in comparison with the boys, the girls may have been discouraged from expressing affect. However, this interpretation of the 3-way interaction reported above should be viewed with extreme caution because of the considerable difference in variance between the groups of children. Further research is needed to examine the attitudes and expectations of families towards health and illness behaviour, and the discussion of affect in the families of both healthy children and children with asthma.

Family dynamics may also facilitate a child's ability to differentiate and describe internal sensations through the parents' sensitivity to and description of their child's respiratory symptoms. For example, were parents' reports of their child's health problems expressed in terms of specific and localised respiratory sensations e.g., 'out of breath', or as non-specific and diffuse feelings e.g., tiredness?

Dunn (1977) described different forms of infant cry that were said to be characteristic of the different states of hunger, pain, loneliness and tiredness. If these different states, signalled by different forms of cry, are the primary physiological states for which an infant develops communicative signals, it is conceivable that tiredness is a primary perception of an internal state. Unless a child has learned to differentiate internal states and develop signal systems to represent those states, any report of how a character might feel after running, playing the recorder, or blowing up several balloons would be characterised by the primary state perceptions with which the child is familiar. If a child learns the signals to represent internal states from his or her caregivers, the sensitivity of the caregivers to the child's internal state, the extent to which the child's internal state is accurately perceived by the caregivers, and the nature of the labels that are used by the caregivers to represent and describe those states, would determine the child's ability to perceive and describe accurately their own subjective, internal state.

It has been suggested that a child learns to label an internal state on the basis of interpretations made by caregivers (Mechanic, 1964; Wilkinson, 1988). In circumstances other than when the caregivers are particularly sensitive to their child's symptoms of respiratory distress, interpretations of out of breath and other specific, internal, respiratory sensations are relatively unlikely to be presented to the child, who may have to rely on characteristic interpretations of infant internal states provided by their caregivers in order to communicate what may be qualitatively different, internal sensations. This has clear implications for the perception and reporting of respiratory symptoms.

In conclusion, the study detected significant associations between a child's age and their attribution of how a character would feel after engaging in a variety of behaviours in which respiratory sensations were likely to be particularly salient. Age and experience of asthma were suggested as determinants of the quality of the children's reports. It was suggested that a child's respiratory awareness and vocabulary develop in the context of family interaction and that particular patterns of interaction within the family are likely to be associated with the child's ability to provide increasingly differentiated and specific reports of their respiratory sensations. The extent to which family discussion may contribute to a child's cognitive representation of asthma is considered further in chapter 7 and chapter 8. Asthma severity and family discussion about asthma as determinants of children's descriptions of respiratory sensations are considered further in study 4.

5.5 Summary

Forty-four 7-8-year-olds and twenty-five 10-11-year-olds were asked to talk about (i) how a character might feel after engaging in various behaviour where breathing may be particularly salient, and (ii) respiratory sensations, breathing, and the respiratory system. The children associated feeling tired and out of breath with blowing up several balloons, playing a long piece of music on a recorder and running to catch a bus. Age and experience of asthma were significant determinants of the children's responses; in comparison with younger children, the older children were more likely to refer to a character feeling out of breath, and in comparison with physically healthy children, children with asthma were more likely to give a detailed description of what out of breath feels like. These detailed descriptions of the children with asthma invariably contained reports of a subjective, internal sensation that was located within the respiratory system. It was suggested that younger children's reports reflect the use of non-specific descriptors such as tiredness, and that the use of such global descriptors originates from the language that caregivers use to label the child's internal state. Older children's reports were suggested to reflect a greater ability to abstract from the concreteness of a situation and the child's acquisition of descriptors associated with the respiratory system. In comparison with physically healthy children, children with asthma were suggested to be more likely to give a detailed description of respiratory sensations because of an increased familiarity with specific, differentiated descriptors. It was suggested that, because only a minority of children with asthma provided a detailed description of what out of breath feels like, the mechanism whereby children acquire the vocabulary to describe respiratory sensations lies beyond the child simply having a history of asthma and experiencing respiratory distress. The development of children's ability to perceive accurately and describe respiratory sensations was therefore suggested to originate in the caregivers' sensitivity to the child's internal state, and from patterns of family interaction in which the discussion of internal states was modelled and encouraged.

Chapter 6

Study 2

6.1 Introduction

The aim of study 2 was to test the reliability of the findings from study 1 concerning children's awareness of respiratory sensations and their attributions of affect (see chapter 5).

6.2 Method

6.2.1 Participants

Ten primary schools in the West Midlands were asked to distribute project information packs to the parents/guardians of Year 3 and Year 6 children with asthma who were identified from school records, and healthy children who were selected at random from class registers. For each child with asthma, teachers were asked to select three healthy pupils. Parents who were willing to allow their child to participate were asked to return a completed consent form to the child's school.

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6.2.2 Instruments

The study instruments (Awareness of respiratory sensations; Demographic and clinical information) are described in chapter 4.

6.2.3 Procedure

Storyboard scenarios (Figure 4.1) were presented to the participants to elicit their attributions of how a character might feel after engaging in the scenario behaviour. Attributions of breathlessness were followed up by a request to talk in greater detail about what out of breath feels like. Participants' responses were recorded at the time of interview using a checklist.

6.2.4 Data Analysis

The children's responses were coded using the framework developed in study 1 (see Table 5.1 and 5.4). Data analysis remained as for study 1.

6.3 Results

All ten schools agreed to distribute the project information packs. Parental consent was given for 187 children, 90 from Year 3 and 97 from Year 6, a response rate similar to that of study 1. Interviews were conducted with 98 boys (52.4%) and 89 girls (47.6%). Forty-eight (25.7%), one hundred and twenty-five (66.8%), and ninety-eight (52.4%) children had a history of asthma, a family history of asthma, or were friends with someone who had asthma respectively. Nineteen children (10.2%) had no experience with asthma. Of the 48 children with asthma, 40 (83.3%) were taking asthma medication. The duration of their diagnosis ranged from 10 months, to 10 years and 10 months (Mean = 6 years and 1 month; SD 2 years and 7 months).

6.3.1 Awareness of Respiratory Sensations

The results of Cochran's test indicated significant differences between scenarios (Table 6.1). The Balloon, Running and Recorder scenarios were particularly likely to elicit attributions of breathlessness. In contrast, the Cold and Recovery scenarios were unlikely to elicit such responses ($\chi 2\,(4) = 438$, $p < 0.001$).

6.3.2 Awareness of Respiratory Sensations: Associations with Age

In comparison with the younger children, the older children were significantly more likely to make attributions of breathlessness in response to the Recorder scenario ($\chi^2\ (1) = 20.00$, $p < 0.001$) (Table 6.2). Analysis of variance of the Out of Breath Total Score by age group, sex and history of asthma also indicated a main effect of age ($F\ (1, 179) = 9.44$, $p < 0.005$). In comparison with the younger children, the older children were also significantly more likely to refer to breathing in response to the Cold ($\chi^2\ (1) = 10.50$, $p < 0.005$) and Recovery scenarios ($\chi^2\ (1) = 8.57$, $p < 0.005$). In contrast, in comparison with older children, the younger children were significantly more likely to make attributions of affect in response to the Recorder scenario ($\chi^2\ (1) = 5.64$, $p < 0.05$).

Table 6.1

Number of Children who made Specific Attributions in Response to Storyboard Stimuli (N = 187)

	Scenario					
Attribution category	Balloon	Running	Recorder	Cold	Recovery	Cochran's χ^2
Out of breath	149 (79.7)	120 (64.2)	130 (69.5)	3 (1.6)	0 (0.0)	438****
Tiredness	154 (82.4)	140 (74.9)	102 (54.5)	42 (22.5)	1 (0.5)	360****
Hotness/Sweating	44 (23.5)	35 (18.7)	62 (33.2)	5 (2.7)	0 (0.0)	131****
Emotion	9 (4.8)	36 (19.3)	84 (44.9)	67 (35.8)	156 (83.4)	292****
Breathing	22 (11.8)	24 (12.8)	31 (16.6)	25 (13.4)	23(12.3)	3
Wheeze	6 (3.2)	8 (4.3)	4 (2.1)	5 (2.7)	0 (0.0)	10*

Note. Percentages are presented in parentheses.

* $p < 0.05$, **** $p < 0.001$

Table 6.2

Chi-Square Analysis of Attributions in Response to Storyboard Stimuli by Age

	Scenario				
Attribution category	Balloon	Running	Recorder	Cold	Recovery
Breathing	0.24	0.21	1.81	10.50***	8.57***
Emotion	0.01	2.02	5.64*	0.15	3.03
Hotness/Sweating	0.33	0.25	8.43*	0.68	-
Out of breath	2.35	0.99	20.00****	1.21	-
Tiredness	0.02	0.14	0.00	5.54*	0.00
Wheeze	1.33	0.06	0.00	2.99	-

Note. The values represent the chi-square statistic. 7-8-year-olds: n = 90; 10-12-year-olds: n = 97.

* $p < 0.05$, *** $p < 0.005$, **** $p < 0.001$

6.3.3 Awareness of Respiratory Sensations: Associations with Asthma

In response to the Balloon scenario, in comparison with the physically healthy, younger children, the younger children with asthma were significantly more likely to refer to breathing (χ^2 (1) = 3.14, Fisher's exact, $p < 0.05$) and significantly less likely to make attributions of tiredness (χ^2 (1) = 9.16, Fisher's exact, $p < 0.005$) (Table 6.3). In response to the Running and Balloon scenarios, in comparison with the physically healthy children, the younger and older children with asthma respectively were significantly more likely to refer to wheeze (χ^2 (1) = 5.45, Fisher's exact, $p < 0.05$ and χ^2 (1) = 5.39, Fisher's exact, $p < 0.05$ respectively) (Table 6.3). Analysis of variance of the Wheeze Total Score by age group, sex and history of asthma indicated a main effect of history of asthma (F (1, 179) = 14.6, $p < 0.001$).

Other than the association with age reported above, there were no significant effects of age group, sex or history of asthma with respect to attributions of affect. However, an analysis of variance of the Hotness/Sweating Total Score by age group, sex and history of asthma revealed a significant 2-way interaction of age group and history of asthma (F (1, 179) = 4.39, $p < 0.05$). There was a main effect of age (F (1, 179) = 4.35, $p < 0.05$). In comparison with the younger children, the older children were more likely to report a character feeling hot or sweaty, and in comparison with the older children with asthma, the older, physically healthy children were less likely to make such attributions (Table 6.4).

6.3.4 Descriptions of What Out of Breath Feels Like

In response to the scenario stimuli, 171 children (91.4%) made attributions of breathlessness. Out of breath was often described in terms of how a character might breathe (35.3% of sample), or as difficulty in breathing (23.0% of sample)

Table 6.3

Chi-Square Analysis of Attributions in Response to Storyboard Stimuli by Age and History of Asthma

	7-8-year-olds[a]				
	Scenario				
Attribution category	Balloon	Running	Recorder	Cold	Recovery
Breathing	3.14*	0.00	1.55	0.00	0.38
Emotion	0.00	0.32	0.23	0.35	2.50
Hotness/Sweating	0.04	1.17	0.88	0.00	-
Out of breath	0.00	0.12	0.01	-	-
Tiredness	9.16***	0.42	0.96	0.66	0.00
Wheeze	0.32	5.45*	2.63	-	-
	10-11-year-olds[b]				
	Scenario				
Attribution category	Balloon	Running	Recorder	Cold	Recovery
Breathing	0.61	0.01	2.32	0.00	0.67
Emotion	0.00	0.61	0.54	0.00	0.26
Hotness/Sweating	0.00	0.04	0.62	0.00	-
Out of breath	0.17	0.06	0.77	0.00	-
Tiredness	0.01	0.00	0.00	1.06	-
Wheeze	5.39*	1.62	2.59	0.05	-

Note. The values represent the chi-square statistic.

[a] Physically healthy: n = 67; History of asthma: n = 23. [b] Physically healthy: n = 72; History of asthma: n = 25.

* $p < 0.05$, *** $p < 0.005$

Table 6.4

Number of Scenarios that Elicited Attributions of Hotness/Sweating by Age and History of Asthma

	Mean number scenarios		Standard deviation		Sample size	
Age	Healthy	Asthma	Healthy	Asthma	Healthy	Asthma
7-8-year-olds	0.63	0.57	0.88	0.95	67	23
10-11-year-olds	0.90	1.04	1.09	1.14	72	25

and tiredness (19.3% of sample). Twenty-two children (11.8%) provided more detailed descriptions of what out of breath feels like. Thirteen of these children had a history of asthma. Although 115 children (61.4%) had some degree of contact with someone who had asthma, only nine of these children (7.8%) provided a reasonably detailed description of what out of breath feels like.

6.3.5 Descriptions of What Out of Breath Feels Like: Associations with Age

Detailed descriptions of what out of breath feels like were significantly associated with age ($\chi 2(1) = 5.34$, $p < 0.05$) (Table 6.5). Age was also significantly associated with the children's descriptions of out of breath in terms of how someone might breathe ($\chi 2(1) = 4.95$, $p < 0.05$) and as difficulty in breathing ($\chi 2(1) = 10.23$, $p < 0.005$).

6.3.6 Descriptions of What Out of Breath Feels Like: Associations with Asthma

Detailed descriptions of what out of breath feels like were significantly associated with experience of asthma (Table 6.6) (for the 7-8-year-olds, $\chi 2(1) = 5.5$, Fisher's exact, $p < 0.05$ and for the 10-11-year-olds, $\chi 2(1) = 6.3$, Fisher's exact, $p < 0.05$). In comparison with the healthy children, the children with asthma were also significantly more likely to describe out of breath as hotness or sweating (for the 7-8-year-olds, $\chi 2(1) = 5.5$, Fisher's exact, $p < 0.05$ and for the 10-11-year-olds, $\chi 2(1) = 3.5$, Fisher's exact, $p < 0.05$). Descriptions of out of breath as difficulty in breathing were associated with the younger children's experience of asthma ($\chi 2(1) = 3.9$, Fisher's exact, $p < 0.05$).

Although the children's detailed descriptions of out of breath invariably referred to subjective, internal sensations, they varied in the amount of detail and the

Table 6.5

Number of Breathlessness Description Categories by Age

Description category	7-8-year-olds[a]	10-11-year-olds[b]
Action of breathing	24 (26.7)	42 (43.3)*
Cough	1 (1.1)	3 (3.1)
Internal sensation	5 (5.6)	17 (17.5)*
Difficulty in breathing	11 (12.2)	32 (33.0)***
Hotness/Sweating	3 (3.3)	6 (6.2)
Tiredness	21 (23.3)	15 (15.5)
Sore throat	0 (0.0)	1 (1.0)
Wheeze	1 (1.1)	4 (4.1)

Note. Percentages are presented in parentheses.

[a] $n = 90$. [b] $n = 97$.

* $p < 0.05$, *** $p < 0.005$

Table 6.6

Number of Breathlessness Description Categories by Age and History of Asthma

	7-8-year-olds	
Description category	Physically healthy[a]	Asthma[b]
Action of breathing	19 (28.4)	5 (21.7)
Cough	0 (0.0)	1 (4.3)
Internal sensation	1 (1.5)	4 (17.4)*
Difficulty in breathing	5 (7.5)	6 (26.1)*
Hotness/Sweating	0 (0.0)	3 (13.0)*
Tiredness	15 (22.4)	6 (26.1)
Sore throat	0 (0.0)	0 (0.0)
Wheeze	0 (0.0)	1 (4.3)

	10-11-year-olds	
Description category	Physically healthy[c]	Asthma[d]
Action of breathing	32 (44.4)	10 (40.0)
Cough	1 (1.4)	2 (8.0)
Internal sensation	8 (11.1)	9 (36.0)*
Difficulty in breathing	21 (29.2)	11 (44.0)
Hotness/Sweating	2 (2.8)	4 (16.0)*
Tiredness	11 (15.3)	4 (16.0)
Sore throat	1 (1.4)	0 (0.0)
Wheeze	1 (1.4)	3 (12.0)

Note. Percentages are presented in parentheses.

[a] n = 67. [b] n = 23. [c] n = 72. [d] n = 25.

* $p < 0.05$

extent to which they referred to internal sensations that were located within the respiratory system. For example, the descriptions of the nine children who had some degree of contact with someone who had asthma were characterised by attributions of tightness in the chest, a need to take deeper breaths and an inability to breathe properly. In contrast, the children with a family history of asthma made attributions of sensations that were experienced in the throat or lungs e.g., "... feels like throat's tightening up" (11-year-old girl whose cousin and friends had asthma); "felt like something stuck in her throat" (8-year-old boy whose aunt had asthma); "like something blocking your lungs" (11-year-old girl whose grandmother and friends had asthma). The majority of children who reported some degree of experience with asthma and who provided a reasonably detailed description of what out of breath feels like were in the older age group.

Sensations that were experienced in the throat or lungs also characterised the descriptions of the children with asthma e.g., "throat would probably feel hard ... tight throat ... dry ... top of throat hurting" (10-year-old boy with asthma that was well-controlled with medication); "chest is heavy ... feel something in her throat" (9-year-old boy with asthma that was poorly-controlled with medication); "throat feels all like funny" (11-year-old girl with asthma that was well-controlled with medication). The sensations experienced in the throat were sometimes elaborated upon, mainly by the younger children with asthma but also by some of the older children with a personal experience of asthma e.g., "feels like his neck goes all cold inside" (8-year-old girl with asthma that was well-controlled with medication); "like something stuck in the throat ... trying to breathe and get it out" (11-year-old girl with asthma that was well-controlled without medication); "cold blocking feeling in his throat ... cough to get it out" (8-year-old boy with asthma that was well-controlled with medication); "throat feels tickly and goes all funny ... feels like there's something coming out ... all bubbly" (8-year-old boy with asthma that was quite poorly-controlled with medication). The older children with asthma provided particularly vivid descriptions of what out of breath feels like. These included "feels like all your body's shrivelling up and it's hard to breathe" (11-year-old boy with asthma that was well-controlled with medication); "feels like you want to take more air in but you can't ... feels as if your lungs have gone all funny and small ... you can't take very much air in" (11-year-old girl with asthma that was well-controlled with medication); "feel like you're all tied up in a straitjacket ... feel wheezy inside ... as if you've got all the body parts in your chest together and can't get any air down your lungs" (11-year-old boy with asthma that was well-controlled with medication).

Although the more detailed descriptions of breathlessness were significantly associated with a child's experience of asthma ($r = 0.28$, $p < 0.001$), their family history of asthma ($r = 0.15$, $p < 0.05$) and their age group ($r = 0.19$, $p < 0.05$), it was not correlated with their age at diagnosis, the duration of their diagnosis, or their parents' perception of disease control.

6.4 Discussion

The study has shown that a child's attributions of respiratory sensations, in particular, feeling out of breath, were significantly associated with the child's age. This is consistent with the findings of study 1. Furthermore, the study has confirmed the significance of experience for the quality of a child's description of breathlessness, over and above any contribution of age. The study has also shown that experience of asthma was associated with a child's attributions of respiratory symptoms. This is consistent with the suggestion that experience of asthma facilitates an awareness and differentiation of respiratory sensations. There was no evidence to support the reliability of the findings from study 1 concerning attributions of affect.

The finding of an association between a child's age and their attributions of feeling out of breath in response to the Recorder scenario lends support to the suggestion that age is associated with an appreciation of the abstract qualities of a situation (Neuhauser et al., 1978). The 10-11-year-olds knew that even a relatively static activity like playing the recorder might be associated with breathlessness. In contrast to the finding of study 1, that the older and younger children were equally likely to attribute breathlessness in response to the Balloon scenario may be explained by stimulus characteristics i.e., the visibility of inflated balloons may have served as an indicator of physical activity.

Alternatively, the extent to which the children remained focused on the topic of the interview may have determined their attributions. For example, the Balloon and Running scenarios were devoid of an interpersonal context. As such, the physical activity cues were perceptually salient and prompted a child's attribution of breathlessness. In contrast, the Recorder scenario introduced a situation where interpersonal associations may have been salient. Although the older and younger children may have been equally likely to recognise the implicit social cues of the situation, the older children may have been more likely to remain focused on the character's breathing. The significant association between a child's age and their talk about breathing in response to the Cold and Recovery scenarios supports this hypothesis. When presented with the Recorder scenario, breathing may have been less perceptually and associatively salient to the younger children because the development of self-perceptions derived from interactions with others (Miell, 1995) may have sensitised them to the social situation and the implications of an individual's behaviour for their evaluation by others. For this reason, they may have construed the Recorder scenario as a social situation associated with socially constructed emotions. This representation may have diverted the younger child's attention from the focus of breathing. The finding that, in comparison with the older children, the younger children were more likely to attribute affect, and less likely to attribute breathlessness, in response to the Recorder scenario is consistent with this hypothesis.[1]

The present study provided additional support for the suggestion that a child's age and their experience with asthma facilitated an awareness of discrete respiratory sensations e.g., breathlessness, chest tightness and wheeze. This suggests that their concept of respiratory sensations had become differentiated from their concepts of primary infant states e.g., tiredness. It is suggested that through discussion with their caretakers, the children with asthma acquired a particularly differentiated concept of respiratory sensations and this was represented through their detailed descriptions of what out of breath feels like. That only a proportion of the children who had experience with asthma provided such detailed descriptions suggested that age and experience of asthma were insufficient as determinants of the quality of the children's descriptions of breathlessness. It is suggested that the extent of discussion with a child about asthma and respiratory symptoms is a further determinant of the quality of their descriptions. Experience of asthma is likely to promote discussion of internal states and respiratory sensations, particularly between a child and their caretakers. It is hypothesised that the detailed descriptions of breathlessness that were provided by a proportion of the children with asthma were contingent upon their discussions about asthma with their parents.

6.5 Summary

To test the reliability of the findings from study 1, ninety 7-8-year-olds and ninety-seven 10-11-year-olds were asked to talk about (i) how a character might

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[1] Although experience in playing a wind instrument was correlated with attributions of feeling out of breath in response to the Recorder scenario, the size of the correlation was small. This suggested that experience in playing a wind instrument made only a small independent contribution to the variance.

feel after engaging in various behaviour where breathing may be particularly salient, and (ii) respiratory sensations. The results suggested that older and younger children might not differ significantly in their linguistic or perceptual competence with respect to attributions of internal states. It was suggested that some of the findings could be explained by the salience of different aspects of a situation and the extent to which children remained focused on breathing i.e., their ability to focus on underlying principles and disregard what may have been developmentally salient features of a scenario. There was no support for the previous findings concerning attributions of affect. Other findings were consistent with those of study 1. Younger children tended to describe out of breath as tiredness, whereas older children were more likely to refer to breathing and components of the respiratory system. It was suggested that the older children's increased differentiation of perceptual concepts enabled their detailed description of specific physical sensations that could be located within the respiratory system. There was also support for the suggestion that children's relevant experience determined the quality of their description of respiratory sensations; in comparison with the physically healthy children, the children with experience of asthma demonstrated a greater awareness and provided a more detailed description of respiratory sensations. Consistent with the findings of study 1, only a proportion of children with asthma provided a detailed description of what out of breath feels like. Relevant experience in the context of family interaction remained a plausible, additional determinant of the quality of the children's descriptions.

Chapter 7

Study 3

7.1 Introduction

Psychological factors and coping strategies may markedly influence the management of patients with chronic severe asthma (Garden & Ayres, 1993). Guidelines for clinically useful research into asthma (European Respiratory Society Task Force on Difficult/Therapy-Resistant Asthma, 1999) and findings from previous research (Sibbald, 1989) indicate that research should further investigate the relationship between beliefs about asthma, clinical phenotypes (the way in which asthma is manifested in different individuals) and health outcome indicators.

Patients' beliefs about illness are associated with patients' health behaviour and health outcome (see chapter 2), and five components of patients' illness beliefs are consistently associated with a variety of significant health behaviours (Petrie & Weinman, 1997). These components include the label and symptoms associated with a disease, expectations about its duration, its perceived cause and consequences, and beliefs about its controllability and cure (Leventhal, Benyamini, Brownlee, Diefenbach, Leventhal, Patrick-Miller & Robitaille, 1997). These components constitute a 'cognitive representation' of illness - the way in which people think about particular aspects of their illness experience.

Although there is now an accumulation of impressive research concerning adults' cognitive representations of their illnesses and its impact on health outcome, much less is known about child patients' perception of their illnesses and its relation to measures of child health.

Children with asthma may experience a variety of psychosocial problems including anxiety, depression and friendship difficulties (Bender & Klinnert, 1998; Graetz & Shute, 1995; Kashani, Konig, Shepperd, Wilfley & Morris, 1988; MacLean, Perrin, Gortmaker & Pierre, 1992; Wamboldt, Fritz, Mansell, McQuaid & Klein, 1998). For many patients these difficulties may disappear once the condition is treated. Nonetheless, there are some patients for whom asthma creates psychosocial problems because it is therapy-resistant (European Respiratory Society Task Force on Difficult/Therapy-Resistant Asthma, 1999). For others, illness may precipitate psychosocial difficulties despite successful medical treatment (Hyland, Ley, Fisher & Woodward, 1995).

Difficult to control asthma may lead to a cycle of psychosocial difficulties and exacerbation of illness (Mattson, 1975). This relationship is likely to be moderated by the children's beliefs about their illness. Furthermore, the underlying determinant of any moderating influence is likely to be affected by the way in which children's beliefs about asthma relate to the system of beliefs within the family. Specifically, concordance between the beliefs about asthma of children and their parents, for example, agreement as to what may trigger asthma, or how to control/prevent symptoms, may be associated with fewer problematic interactions concerning the child's disease. Belief concordance may also be associated with the child's perception of family support and understanding. Concordance in the beliefs of mothers and their child about the impact of the child's asthma has been attributed to their shared concerns about the child's asthma that may have been expressed within the child's family (Khampalikit, 1983). Shared concern and the provision of appropriate emotional support within the families of children with asthma was negatively associated with children's self-reported distress about their asthma and its consequences (Sawyer, Spurrier, Kennedy & Martin, 2001).

The goals of childhood asthma management include the abolition of symptoms, the achievement of optimal lung function, a reduction in the risk of severe attacks and minimised disruption to school attendance (British Guidelines on Asthma Management, 1997; Guidelines on the Management of Asthma, 1993). These goals are achieved by varying the type and dose of medication to achieve effective control of the disease (The British Guidelines on Asthma Management, 1997). This may involve 'stepping up' or 'stepping down' the use of short- or long-acting bronchodilators and inhaled or oral steroids (anti-inflammatory medication). Other recommendations include the avoidance of precipitating factors. The emphasis is placed on guided self-management (Guidelines on the Management of Asthma, 1993). For this reason, patients' motivation to initiate and maintain recommended self-management behaviours is likely to be a central component of the asthma management system and a significant determinant of patients' success in achieving control of their condition.

Theoretical advances in health psychology have started to concentrate on clarifying the role of beliefs in the initiation and maintenance of health behaviour through improving either an individual's motivation or volition with respect to engaging in specific health-related behaviours (e.g., Abraham et al., 1998; Fuhrmann & Kuhl, 1998). Encouraging patients and their carers to work towards goals that they themselves have set has been emphasised as a key component of effective asthma management (Clark, 1998). Childhood asthma sufferers' (and their parents') reasons for achieving good control of asthma may serve to motivate their asthma management behaviour. The same reasons also are likely to indicate the aspects of childhood asthma sufferers' and their parents' daily lives that are affected by the experience of asthma. These matters are of particular relevance as low adherence with treatment recommendations has been reported in the literature (Deaton, 1985; Fritz & Wamboldt, 1998; Hilton, 1991) and because chronic disease and its treatment may influence quality of life (Eiser & Morse, 2001; Hutchinson et al., 1996; Juniper, 1998).

The study reported in the present chapter involved a group of children with asthma (and their parents/guardians). The aims of the study and its constituent analyses are described in Chapter 4.

7.2 Method

7.2.1 Participants

Participants were 10-11-year-olds with asthma attending state primary schools in the Midlands and their parents. Seventy-two of 114 headteachers (response rate 63%) distributed a total of 3449 information packs to the parents of all pupils in the appropriate age range. Reasons for non-participation included no children with a history of asthma and difficulties within the school at the time of recruitment. Parents/guardians who identified their child as having had asthma for at least one year, whose child was currently taking asthma medication, and who were willing to participate, were asked to return the contact form in a reply paid envelope. Only one distribution was undertaken.

7.2.2 Instruments

The study instruments (Demographic and clinical information; Illness Perception Questionnaire; Semi-structured interview; Sophistication of verbal representation of asthma; Belief concordance; Strengths and Difficulties Questionnaire; Reasons for achieving good control of asthma) are described in chapter 4.

7.2.3 Procedure

All parents were asked to give written informed consent prior to interview and all children were asked to give verbal assent at the time of interview. Individual interviews lasted between a half and one hour. The interviews were conducted at the participants' home or at the child's school. Interviews with the parent preceded the interview with the child in most instances and took place without the child present. Most parents chose to attend the child interview. In all instances the semi-structured interview preceded first, the IPQ, second, the SDQ, and third, the cognitive task to elicit reasons for achieving good control of asthma. Responses to the semi-structured interview were recorded verbatim at the time of interview. On some occasions the IPQ and SDQ were completed without the assistance of the interviewer. At other times, at the request of a participant, the interviewer read out questionnaire items and recorded the participant's response.

7.2.4 Data Analysis 1

Data from the semi-structured interview were analysed using a pre-determined framework that corresponded to the six different components of the cognitive representation of asthma. Chi-square tests or their exact-probability equivalents were used to examine group differences. Group differences in the degree of sophistication of the participants' verbal representation of asthma were examined using a paired-samples t-test.

Data from the Illness Perception Questionnaire were analysed using paired-samples t-tests and Sign tests. Correlations between demographic and disease variables, illness beliefs and concordance in the beliefs of the parents and their child were examined.

7.2.5 Data Analysis 2

Data from the Strengths and Difficulties Questionnaire were analysed using paired-samples t-tests. Correlations between participants' beliefs about asthma, belief concordance and the children's parent- and self-reported psychological well-being were examined.

7.2.6 Data Analysis 3

Reasons for achieving good control of asthma were derived using inductive content analysis, and were examined with respect to abstractness (the extent to which a reason was a destination of a pathway rather than a source), centrality (the extent to which a reason was involved in links with other reasons) and prestige (the extent to which a reason was a target of other reasons).

The study was granted approval by a University Research Ethics Committee.

7.3 Results

Parental consent was given for 49 children, which on the basis that 20% of primary school age children have asthma (ISAAC Steering Committee, 1998), suggests a response rate of around 7%. Seven children and their parents were not included in the study because they did not meet the study inclusion criteria. Two parents provided no contact details and three, who initially expressed an interest, subsequently declined to take part.

Of the 37 participating families, four families were excluded from analysis because of incomplete data (n = 1), concern about the participants' understanding of the questions that were asked (and the researcher's understanding of the participants' responses) (n = 2) and because the data obtained from a young 10-year-old participant were qualitatively different from the data of the older children (n = 1). Data from two respondents, twins, were excluded because the parents' responses concerning each child were not independent.

In total, interviews were conducted with nineteen boys, twelve girls, twenty-nine mothers and two fathers. The demographic characteristics of the families and the clinical characteristics of the children with asthma are presented in Table 7.1 and Table 7.2. In all instances, the parents who participated were the primary caregivers for the child.

Table 7.1

Demographic Characteristics of the Sample

	Mean	SD	Range
Age of parent (years)	39.9	5.5	30 - 50
Age of child (years.months)	11.1	0.3	10.5 - 11.7
Duration of asthma (years.months)	7.6	2.6	2.2 - 11.0
Jarman Underpriviliged Area Score[a]	0.3	17.4	-39.4 - 34.2
	n	**%**	
Sex of parent			
Male	2	6.5	
Female	29	93.5	
Sex of child			
Male	19	61.3	
Female	12	38.7	
Marital status			
Married or cohabiting	19	61.3	
Single parent household	12	38.7	
Occupation			
Middle class	18	58.1	
Working class	7	22.6	
Housewife/husband	5	16.1	
Unemployed	0	0.0	
Student	1	3.2	
Number of children in household			
1	5	16.1	
2	12	38.7	
3	7	22.6	
4	7	22.6	
Number of smokers in household			
0	14	45.2	
1	15	48.4	
2	1	3.2	
3	1	3.2	

[a] The mean and standard deviation of the distribution of ward scores in England and Wales reported by Jarman (1984) were 0 and 16.0 respectively. Higher scores are associated with social indicators of underprivilege.

Table 7.2

Clinical and Historical Characteristics of the Sample

	n	%
Other with a history of asthma living in the household		
No	16	51.6
Yes	15	48.4
Age at diagnosis (years)		
Younger than or equal to 3	18	58.1
Between 3 and 5	6	19.3
Older than 5	7	22.6
Step of treatment[a]		
Step 0	2	6.5
Step 1 or 2	27	87.1
Step 3	1	3.2
Indeterminate	1	3.2
Perceived control of asthma		
1 Very poorly controlled	0	0.0
2	0	0.0
3	0	0.0
4	0	0.0
5	6	19.4
6	11	35.5
7 Very well controlled	14	45.2

[a] Step of treatment was determined by a respiratory paediatrician, blind to the responses of the participants.

7.3.1 Data Analysis 1

Semi-structured Interview

The participants' response to an open-ended request for information about the child's asthma was coded for the occurrence of discourse corresponding to the six components of illness representation: (i) Identity, (ii) Cause, (iii) Cause of Exacerbation, (iv) Time-Line, (v) Consequences, and (vi) Cure/Control. Two independent raters coded a random selection of ten interview transcripts. Although concerning seven of thirty-eight passages of text there was a disagreement about the passages' eligibility for coding, Cohen's kappa coefficient for the remaining 31 segments was 0.96. Disagreements were discussed and whenever possible resolved.

The parents' discourse most often related to the illness representation components of Identity, Cause of Exacerbation, Time-Line and Consequences (Table 7.3). 'Cause' was represented much less often. Just over half of the adult respondents referred to 'Cure/Control'. The result of Cochran's test was significant (χ^2 (5) = 45.5, $p <$ 0.001) and indicated that the illness representation components differed in the likelihood of their occurrence in the parents' spontaneous discourse about asthma.

The children's discourse most often related to the Identity and Consequences components of illness representation (Table 7.3). 'Cause', 'Time-Line' and

Table 7.3

Number of Spontaneous Verbal Representations of IPQ Components by Respondent

IPQ component	Parents[a]	Children[a]
Identity	29 (93.5)	21 (67.7)*
Cause	7 (22.6)	0 (0.0)*
Exacerbation	25 (80.6)	16 (51.6)*
Time-Line	22 (71.0)	12 (38.7)*
Consequences	27 (87.1)	23 (74.2)
Cure/Control	18 (58.1)	8 (25.8)*

Note. Percentages are presented in parentheses.

[a] $n = 31$.

* $p < 0.05$

'Cure/Control' were represented much less often. The result of Cochran's test was significant (χ^2 (5) = 49.6, $p < 0.001$).

McNemar's test indicated that, although an equivalent proportion of the parents and the children represented the Consequences component of illness representation in their discourse, in comparison with the parents, a significantly smaller proportion of the children represented 'Identity', 'Cause', 'Cause of Exacerbation', 'Time-Line' and 'Cure/Control'.

Sophistication of the Participants' Verbal Representation of Asthma

In comparison with the children, the parents represented significantly more illness representation components in their discourse (Parents: Mean = 4.13, SD 0.96; Children: Mean = 2.58, SD 1.31) (t (30) = 5.5, $p < 0.001$). A child's sophisticated verbal representation was significantly associated with their parents' age (r (27) = 0.56, $p < 0.005$) and the duration of their parents' pre-diagnosis awareness of the child's respiratory difficulties (r (26) = -0.50, $p < 0.01$).

Illness Perception Questionnaire

IPQ-P

Breathlessness, wheeze and chest tightness were the main physical difficulties that parents associated with their child's asthma (Table 7.4). To a slightly lesser extent, parents reported that their child had experienced fatigue (64.5% of sample) and a sore throat (61.3% of sample). The result of Cochran's test was significant (χ^2 (20) = 221, $p < 0.001$) and indicated that the various signs and symptoms differed in the likelihood that they would be associated with asthma.

The majority of the parents believed that heredity was an original cause of their child's asthma and just under half believed that pollution was implicated (Table 7.5). The least frequently cited causes of asthma were their child's behaviour, their child's state of mind, diet, stress and poor medical care in the past. There was a significant difference in the extent to which the cause of asthma was attributed to the different factors (Friedman two-way analysis of variance by ranks, χ^2 (11) = 93, $p < 0.001$).

The majority of the parents believed that cigarette smoke and pollution could trigger their child's asthma (Table 7.6). Other triggers included being near cats, or dogs, or other animals, and their child's state of mind. Just over half of the parents believed that stress was a trigger. There was a significant difference in the extent to which the

Table 7.4

Cognitive Representation of Asthma Identity by Respondent

Identity component	Parents[a]		Children[a]	
Pain	12	(38.7)	22	(71.0)
Nausea[b]	15	(48.4)	9	(29.0)
Breathlessness[b]	31	(100.0)	30	(96.8)
Weight gain[b]	7	(22.6)	5	(16.1)
Fatigue[b]	20	(64.5)	29	(93.5)
Tight chest	27	(87.1)	26	(83.9)
Panic attacks[b]	14	(45.2)	18	(58.1)
Headaches[b]	16	(51.6)	17	(54.8)
Upset stomach[b]	12	(38.7)	16	(51.6)
Sleep difficulties[b]	17	(54.8)	23	(74.2)
Nervous tension[b]	9	(29.0)	16	(51.6)
Weight loss[b]	2	(6.5)	2	(6.5)
Spots	4	(12.9)	5	(16.1)
Sore eyes	6	(19.4)	14	(45.2)
Toothache[c]	0	(0.0)	2	(6.5)
Anxiety[b]	13	(41.9)	16	(51.6)
Sore throat	19	(61.3)	23	(74.2)
Wheezing	28	(90.3)	30	(96.8)
Hair falling out[c]	0	(0.0)	0	(0.0)
Dizziness[b]	12	(38.7)	19	(61.3)
Feeling shakey[c]	-	-	11	(35.5)
Loss of strength[b]	8	(25.8)	21	(67.7)

Note. Values represent the number of participants who endorsed each response option. Percentages are presented in parentheses.

[a] n = 31. [b] IPQ-C version presented in Table 4.2. [c] Item included to control for automatic or hypochondriacal responding.

Table 7.5

Cognitive Representation of the Causes of Asthma by Respondent

Cause	Parents[a]					Children[a]				
	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Germ or virus	2 (6.5)	1 (3.2)	3 (9.7)	10 (32.3)	15 (48.4)	0 (0.0)	3 (9.7)	14 (45.2)	12 (38.7)	2 (6.5)***
Diet[b]	1 (3.2)	1 (3.2)	4 (12.9)	12 (38.7)	13 (41.9)	0 (0.0)	0 (0.0)	9 (29.0)	13 (41.9)	9 (29.0)
Pollution[b]	5 (16.1)	8 (25.8)	10 (32.3)	5 (16.1)	3 (9.7)	1 (3.2)	14 (45.2)	10 (32.3)	6 (19.4)	0 (0.0)
Heredity[b]	5 (16.1)	16 (51.6)	3 (9.7)	2 (6.5)	5 (16.1)	4 (12.9)	8 (25.8)	7 (22.6)	8 (25.8)	4 (12.9)
Chance[b]	2 (6.5)	3 (9.7)	7 (22.6)	10 (32.3)	9 (29.0)	3 (9.7)	11 (35.5)	8 (25.8)	6 (19.4)	3 (9.7)*
Stress	1 (3.2)	1 (3.2)	3 (9.7)	15 (48.4)	11 (35.5)	0 (0.0)	3 (9.7)	3 (9.7)	14 (45.2)	11 (35.5)
Child's behaviour[b]	0 (0.0)	0 (0.0)	0 (0.0)	15 (48.4)	16 (51.6)	0 (0.0)	2 (6.5)	6 (19.4)	4 (12.9)	19 (61.3)
Other people's fault	0 (0.0)	4 (12.9)	2 (6.5)	11 (35.5)	14 (45.2)	1 (3.2)	0 (0.0)	2 (6.5)	10 (32.3)	18 (58.1)
Poor medical care in the past	1 (3.2)	1 (3.2)	1 (3.2)	12 (38.7)	16 (51.6)	0 (0.0)	0 (0.0)	1 (3.2)	13 (41.9)	17 (54.8)
No-one's fault	11 (35.5)	13 (41.9)	4 (12.9)	2 (6.5)	1 (3.2)	14 (45.2)	14 (45.2)	2 (6.5)	1 (3.2)	0 (0.0)
Child's state of mind[b]	0 (0.0)	1 (3.2)	3 (9.7)	14 (45.2)	13 (41.9)	0 (0.0)	0 (0.0)	8 (25.8)	13 (41.9)	10 (32.3)

Note. Values represent the number of participants who endorsed each response option. Percentages are presented in parentheses.

[a] n = 31. [b] IPQ-C version presented in Table 4.3.

* $p < 0.05$, *** $p < 0.005$

Table 7.6

Cognitive Representation of the Causes of an Exacerbation of Asthma by Respondent

	Parents[a]					Children[a]				
Cause of Exacerbation	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Diet[b]	1 (3.2)	7 (22.6)	7 (22.6)	8 (25.8)	8 (25.8)	0 (0.0)	4 (12.9)	10 (32.3)	11 (35.5)	6 (19.4)
Pollution[b]	8 (25.8)	15 (48.4)	6 (19.4)	2 (6.5)	0 (0.0)	5 (16.1)	17 (54.8)	5 (16.1)	3 (9.7)	1 (3.2)
Chance[b]	0 (0.0)	2 (6.5)	5 (16.1)	21 (67.7)	3 (9.7)	1 (3.2)	2 (6.5)	6 (19.4)	7 (22.6)	15 (48.4)
Stress	1 (3.2)	15 (48.4)	5 (16.1)	8 (25.8)	2 (6.5)	0 (0.0)	6 (19.4)	7 (22.6)	10 (32.3)	8 (25.8)**
Being near cats or dogs	8 (25.8)	12 (38.7)	2 (6.5)	8 (25.8)	1 (3.2)	3 (9.7)[c]	6 (19.4)[c]	4 (12.9)[c]	12 (38.7)[c]	5 (16.1)[c]**
Cigarette smoke	14 (45.2)	13 (41.9)	1 (3.2)	3 (9.7)	0 (0.0)	12 (38.7)[c]	16 (51.6)[c]	2 (6.5)[c]	0 (0.0)[c]	0 (0.0)[c]
Child's behaviour[b]	0 (0.0)	2 (6.5)	2 (6.5)	12 (38.7)	15 (48.4)	1 (3.2)	3 (9.7)	7 (22.6)	8 (25.8)	12 (38.7)
Other people's fault	0 (0.0)	1 (3.2)	1 (3.2)	13 (41.9)	16 (51.6)	1 (3.2)	0 (0.0)	2 (6.5)	10 (32.3)	18 (58.1)
Doctors' and nurses' fault	0 (0.0)	0 (0.0)	2 (6.5)	8 (25.8)	21 (67.7)	0 (0.0)	0 (0.0)	2 (6.5)	9 (29.0)	20 (64.5)
No-one's fault	6 (19.4)	11 (35.5)	8 (25.8)	5 (16.1)	1 (3.2)	11 (35.5)	15 (48.4)	3 (9.7)	2 (6.5)	0 (0.0)
Child's state of mind[b]	0 (0.0)	20 (64.5)	4 (12.9)	4 (12.9)	3 (9.7)	0 (0.0)	5 (16.1)	16 (51.6)	7 (22.6)	3 (9.7)*

Note. Values represent the number of participants who endorsed each response option. Percentages are presented in parentheses.

[a] n = 31. [b] IPQ-C version presented in Table 4.4. [c] n = 30.

* $p < 0.05$, ** $p < 0.01$

cause of an exacerbation of asthma was attributed to the different factors (Friedman two-way analysis of variance by ranks, χ^2 (11) = 165, p < 0.001).

Overall, the parents were quite uncertain about the Time-Line of their child's condition (Table 7.7). However, in comparison with the proportion of the parents who expressed an acute Time-Line belief, a higher proportion believed that their child's asthma was chronic.

As a group, the parents expressed a belief that asthma generally, and their child's asthma specifically, was a serious medical condition, although its consequences were not serious (Table 7.8). The majority of the parents believed that their child's asthma was controllable (Table 7.9).

IPQ-C

From the children's perspective, their asthma was characterised by breathlessness, wheeze, tiredness, chest tightness, pain, sleep difficulties and a sore throat (Table 7.4). The result of Cochran's test was significant (χ^2 (20) = 250, p < 0.001) and indicated that the various signs and symptoms differed in the likelihood that they would be associated with asthma.

Just under half of the children believed that pollution was a cause of their asthma (Table 7.5). Fewer children (38.7%) believed that heredity was implicated. Diet, their

Table 7.7

Cognitive Representation of the Time-Line of Asthma by Respondent

Time-Line	Parents[a]					Children[a]				
	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Acute[b]	0 (0.0)	4 (12.9)	13 (41.9)	10 (32.3)	4 (12.9)	0 (0.0)	2 (6.5)	18 (58.1)	9 (29.0)	2 (6.5)
Chronic[b]	2 (6.5)	6 (19.4)	17 (54.8)	5 (16.1)	1 (3.2)	2 (6.5)	4 (12.9)	22 (71.0)	3 (9.7)	0 (0.0)

Note. Values represent the number of participants who endorsed each response option. Percentages are presented in parentheses.

[a] n = 31. [b] IPQ items presented in Table 4.5.

Table 7.8

Cognitive Representation of the Consequences of Asthma by Respondent

	Parents[a]					Children[a]				
Consequences item [b]	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Generally a serious condition	5 (21.7)[c]	10 (43.5)[c]	3 (13.0)[c]	4 (17.4)[c]	1 (4.3)[c]	1 (4.8)[d]	7 (33.3)[d]	5 (23.8)[d]	5 (23.8)[d]	3 (9.7)[d]
Child's asthma is serious	5 (16.1)	10 (32.3)	4 (12.9)	7 (22.6)	5 (16.1)	0 (0.0)	10 (32.3)	5 (16.1)	13 (41.9)	3 (9.7)
Major consequences	1 (3.2)	7 (22.6)	3 (9.7)	13 (41.9)	7 (22.6)	3 (9.7)	17 (54.8)	2 (16.5)	6 (19.4)	3 (9.7)***

Note. Values represent the number of participants who endorsed each response option. Percentages are presented in parentheses.

[a] n = 31. [b] IPQ items presented in Table 4.6. [c] n = 23. [d] n = 21.

*** $p < 0.005$

Table 7.9

Cognitive Representation of the Cure/Control of Asthma by Respondent

	Parents[a]					Children[a]				
Cure/Control[b]	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Child's state of mind	0 (0.0)	18 (58.1)	5 (16.1)	6 (19.4)	2 (6.5)	0 (0.0)	6 (19.4)	17 (54.8)	4 (12.9)	4 (12.9)
A lot child can do	4 (12.9)	22 (71.0)	4 (12.9)	1 (3.2)	0 (0.0)	1 (3.2)	13 (41.9)	13 (41.9)	2 (6.5)	2 (6.5)***
Treatment (control)	6 (19.4)	24 (77.4)	1 (3.2)	0 (0.0)	0 (0.0)	5 (16.1)	21 (67.7)	2 (6.5)	3 (9.7)	0 (0.0)
Treatment (cure)	0 (0.0)	1 (3.2)	7 (22.6)	17 (54.8)	6 (19.4)	0 (0.0)	0 (0.0)	24 (77.4)	7 (22.6)	0 (0.0)***
Recovery (chance)	0 (0.0)	8 (25.8)	5 (16.1)	10 (32.3)	8 (25.8)	2 (6.5)	8 (25.8)	7 (22.6)	12 (38.7)	2 (6.5)
What child does	1 (3.2)	16 (51.6)	8 (25.8)	5 (16.1)	1 (3.2)	5 (16.1)	14 (45.2)	9 (29.0)	3 (9.7)	0 (0.0)

Note. Values represent the number of participants who endorsed each response option. Percentages are presented in parentheses.

[a] $n = 31$. [b] IPQ items presented in Table 4.7.

*** $p < 0.005$

state of mind and poor medical care in the past were least often cited by the children as causes of their asthma The result of a Friedman test, conducted to evaluate differences among the beliefs of the children concerning the causes of asthma, was significant (χ^2 (10) = 126, p < 0.001).

The majority of the children expressed a belief that cigarette smoke and pollution were triggers of their asthma, although just over half were uncertain about whether an exacerbation could be linked with their state of mind (Table 7.6). The result of a Friedman test, conducted to evaluate differences among the beliefs of the children concerning the causes of an exacerbation of asthma, was significant (χ^2 (10) = 121, p < 0.001).

The majority of the children were uncertain about the Time-Line of their asthma (Table 7.7). However, in comparison with the proportion of the children who expressed an acute Time-Line belief, a higher proportion expressed a belief that their condition was chronic.

The children were divided as to whether asthma generally was a serious medical condition and just under one third considered their asthma, specifically, to be serious (Table 7.8). Although the children, as a group, considered their asthma to have had big effects on things they could do, overall, they believed that its consequences were not serious.

As with the other components of illness representation, there was considerable uncertainty amongst the children concerning Cure/Control (Table 7.9). Just over half were unsure about whether their state of mind could make their asthma better, and the majority were unsure about whether their treatment could cure their asthma. However, the majority of the children did believe that their treatment was effective in controlling their asthma and that what they did could determine whether their asthma got better or worse.

Illness Perception Questionnaire: Between Group Comparisons

Although the Identity scores of the parents and their child were significantly associated ($r = 0.42$; $n = 31$, $p < 0.05$), in comparison with their parents, the children reported a greater number of signs and symptoms (Parents: Mean 8.77, SD 3.74; Children: Mean 11.06, SD 3.78) (paired-sample t-test, t (30) = -3.15, $p < 0.005$). In comparison with their parents, the children were more uncertain about the aetiology of their asthma, and in particular the role of a germ or virus (Sign test, using the binomial distribution, $p < 0.05$). They were also more likely to attribute their condition to chance (Sign test, using the binomial distribution, $p < 0.05$). In comparison with their children, the parents expressed stronger agreement that stress (Sign test, using the binomial distribution, $p < 0.01$), proximity to cats, or dogs, or other animals (Sign test, using the binomial distribution, $p < 0.01$), and the child's state of mind (Sign test, using the binomial distribution, $p < 0.05$) were triggers of the child's asthma. A paired-samples t-test indicated no significant difference between the parents' and the children's mean Time-Line score (Parents: Mean 6.55, SD 1.61; Children: Mean 6.52, SD 1.18), and between the parents' and the children's mean Consequences score (Parents: Mean 14.81, SD 4.05; Children: Mean 15.70, SD 3.98). However, although the majority of the parents (64.5%) expressed a belief that asthma had not had major consequences for their child's life, the majority of the children (64.5%) expressed a belief that asthma had big effects on things they could do (Sign test, using binomial distribution, $p < 0.005$). Eighty-six percent of the differences between the parents' and the children's strength and direction of belief in the extent to which asthma had major consequences for their child's life/big effects on things the child could do were in the direction of expressed greater agreement amongst the children that asthma had big effects on things they could do.

In comparison with the children, the parents considered asthma to be more controllable (Parents: Mean 8.06, SD 1.06; Children: Mean 6.87, SD 1.38) (t (30) = -3.91, $p < 0.001$) and expressed stronger agreement that there was a lot that their child could do to control the symptoms of asthma (Sign test, using binomial distribution, $p < 0.005$). In comparison with the parents, the children expressed greater uncertainty about whether their treatment would cure their asthma (Sign test, using binomial distribution, $p < 0.005$).

Beliefs about Asthma: Associations with Demographic Factors and Illness Characteristics

The parents' and the children's beliefs about heredity as a cause of asthma were significantly associated with a household member (other than the index child) having asthma ($r = 0.51$; $n = 31$, $p < 0.005$) and with the child's age at diagnosis ($r = 0.50$; $n = 31$, $p < 0.005$) respectively.

Beliefs about Asthma: Associations Between the Illness Representation Components

The parents' belief that stress was a trigger of their child's asthma was significantly associated with their belief that the child's state of mind was also a trigger ($r = 0.46$; $n = 31$, $p < 0.01$). The parents' perception of the extent to which their child's asthma was well controlled was significantly negatively associated with their perception of serious consequences ($r = -0.52$; $n = 31$, $p < 0.005$). The children's Identity belief (the number of signs and symptoms that were associated with asthma) was significantly associated with their belief about the seriousness of the consequences of their asthma ($r = 0.50$; $n = 31$, $p < 0.005$).

Beliefs about Asthma: Concordance in Beliefs of the Parents and their Children about Asthma

The proportion of concordant responses was calculated for each of the six illness representation components: (i) Identity, (ii) Cause, (iii) Cause of Exacerbation, (iv) Time-Line, (v) Consequences, and (vi) Cure/Control. Means and standard deviations are presented in Table 7.10.

The parents' and the children's beliefs were most concordant concerning the signs and symptoms (Identity) of the child's asthma. There was slightly less concordance about 'Cause' and 'Cause of Exacerbation'. Least concordance was evident concerning 'Consequences', 'Cure/Control' and 'Time-Line'.

Repeated measures analysis of variance, with Greenhouse-Geisser correction, indicated significant differences in the proportion of belief concordance between the different illness representation components (F (2.73, 79.13) = 17.6, $p < 0.001$). Post hoc paired-samples t-test with Bonferroni adjustment indicated significantly greater concordance for 'Identity' in comparison with 'Consequences' (t (30) = 14.78, $p < 0.001$), 'Cure/Control' (t (30) = 6.16, $p < 0.001$), 'Time-Line' (t (30) = 4.40, $p < 0.001$) and 'Cause of Exacerbation' (t (29) = -3.56, $p < 0.005$), 'Cause' in comparison with 'Consequences' (t (30) = 7.93, $p < 0.001$) and 'Cure/Control' (t (30) = 4.03, $p < 0.001$), 'Cause of Exacerbation' in comparison with 'Consequences' (t (29) = 8.45, $p < 0.001$) and 'Cure/Control' (t (29) = 3.61, $p < 0.005$), and

Table 7.10

Proportion of Concordance in the IPQ Beliefs of the Parents and their Child by IPQ component

IPQ component	Mean proportion concordance	Standard deviation
Identity	0.70	0.11
Cause	0.62	0.17
Exacerbation	0.58	0.13
Time-Line	0.43	0.32
Consequences	0.30	0.16
Cure/Control	0.46	0.20

Note. The mean proportion of concordance in the beliefs of the parents and their child was calculated from the data of 31 parent-child pairings.

'Cure/Control' in comparison with 'Consequences' (t (30) = -3.40, $p < 0.005$). A total Belief Concordance score was also calculated for each participant by summing the total number of concordant beliefs. This ranged between 26 and 49 (Mean 34.6, SD 4.6).

Correlations between the IPQ-P and the IPQ-C suggested poor concordance, with the exception of Identity beliefs ($r = 0.42$; $n = 31$, $p < 0.05$), beliefs about heredity as a cause of asthma ($r = 0.46$; $n = 31$, $p < 0.01$), and beliefs about contact with animals as a potential trigger ($r = 0.47$; $n = 31$, $p < 0.01$).

Belief Concordance: Associations with Demographic Factors and Illness Characteristics

Concordance in the beliefs of the parents and their child about asthma were not significantly correlated with any demographic factor or illness characteristic.

7.3.2 Data Analysis 2

Strengths and Difficulties Questionnaire

The mean Total Difficulties scores were within the normal range, as were all sub-scale scores (Table 7.11). Children reported themselves as having significantly more conduct problems (mean difference 1.03, 95% CI 0.23 to 1.83, $p < 0.05$) and engaging in significantly less pro-social behaviour (mean difference –0.97, 95% CI –1.79 to –0.14, $p < 0.05$) than did their parents.

Parent-reported difficulties with their child were more frequent than children's self-reported difficulties (Table 7.11). In particular, parents reported hyperactivity, emotional symptoms and peer problems, whereas conduct problems were most reported by the children. Pro-social behaviour problems were reported least often. Fewer children reported peer problems than their parents (McNemar test, using binomial distribution, $p < 0.05$).

Seventeen parents (54.8%) and twenty-one children (67.7%) reported minor, definite or severe difficulties in one or more of the areas of emotions, concentration, behaviour or being able to get on with other people. Seven parents (22.6%) and eleven children (35.5%) reported difficulties that the other participant of the parent-child pair did not.

Table 7.11

Strengths and Difficulties of Children with Asthma

SDQ scale	Mean		Standard deviation		Number of cases[a]	
	Parent's reports[b]	Children's reports[b]	Parents' reports[b]	Children's reports[b]	Parents' reports[b]	Children's reports[b]
Conduct Problems	2.00	3.03*	1.79	1.97	5 (16.0)	7 (23.0)
Hyperactivity	4.39	4.10	2.70	1.96	8 (26.0)	3 (10.0)
Emotional Symptoms	2.94	3.71	2.49	2.07	7 (23.0)	3 (10.0)
Peer Problems	1.87	1.71	1.86	1.49	7 (23.0)	1 (3.0)*
Pro-social Behaviour	8.00	7.03*	2.13	1.68	0 (0.0)	0 (0.0)
Total Difficulties	11.19	12.55	6.07	5.17	6 (19.0)	3 (10.0)

[a] Values represent the number of participants who endorsed each response option. Percentages are presented in parentheses. [b] $n = 31$.

* $p < 0.05$

Children's Psychological Well-Being: Associations with Beliefs about Asthma

Parents' beliefs about asthma, and in particular beliefs about the consequences of asthma, were significantly associated with their reports of their child's psychological well-being (Table 7.12). Although concordance between the Identity belief of the parents and their child was significantly negatively associated with the parents' reports of their child's conduct problems ($r = -0.40$; $n = 31$, $p < 0.05$), overall, in comparison with the children's self-reports, belief concordance was less strongly associated with the children's parent-reported psychological well-being. Demographic factors and illness characteristics were significantly associated with the children's parent-reported difficulties (Table 7.12).

Children's perception of the consequences of their asthma, and belief that heredity was a cause of asthma were positively associated with their self-reported difficulties (Table 7.13). Although demographic factors and illness characteristics were independent of the children's self-reported psychological well-being, concordance in the beliefs of the children and their parents concerning the consequences of the child's asthma was significantly negatively associated with the children's self-reported difficulties (Table 7.13).

Table 7.12

Correlations between the parents' beliefs about their child's asthma, demographic factors, illness characteristics and their child's parent-reported psychological well-being

	SDQ scale						
Beliefs about asthma	TDS	IS	CP	H	ES	PP	PSB
Illness Identity	.30	.36*	.02	.04	.45*	.30	.14
Time-Line	-.19	-.06	.02	-.16	-.13	-.22	.12
Consequences	.56***	.43*	.33	.40*	.37*	.44*	-.12
Cure/Control	-.04	-.34	.04	-.10	.07	-.11	.02
Perceived control of asthma	-.10	-.15	-.27	.01	-.04	-.02	.06
	SDQ scale						
Demographic factor	TDS	IS	CP	H	ES	PP	PSB
Age of parent	-.26	-.14	-.39*	-.17	-.09	-.14	-.01
Sex of parent[a]	.32	.14	.30	.24	.10	.27	.00
Single parent household	.26	.40*	.04	.08	.21	.42*	.03
Number of children	.11	.01	.25	.03	.11	-.09	-.02
Number of smokers	.42*	.47**	.34	.11	.36*	.39*	.15
Underprivileged area score	.28	.16	.13	.05	.22	.42*	-.14
	SDQ scale						
Illness characteristic	TDS	IS	CP	H	ES	PP	PSB
Age at diagnosis	-.13	-.16	.10	-.15	-.22	-.01	.14
Duration of diagnosis	.11	.13	-.11	.12	.21	.02	-.13
Duration of pre-diagnosis awareness	.26	.39*	.01	.02	.21	.55***	-.00
Time since last attack	-.06	-.04	-.18	.09	-.07	-.03	.22

Note. TDS Total Difficulties; IS Impact; CP Conduct Problems; H Hyperactivity; ES Emotional Symptoms; PP Peer Problems; PSB Pro-social Behaviour.

Note. n = 31.

[a] 1 = Male, 2 = Female.

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.005$

Table 7.13

Correlations between children's beliefs about their asthma, concordance in beliefs of parents and their child, and children's self-reported psychological well-being

	SDQ scale					
Beliefs about asthma	TDS	CP	H	ES	PP	PSB
Illness Identity	.41*	.29	.16	.47**	.16	.36*
Cause - Heredity	.44*	.40*	.30	.00	.62****	.00
Time-Line	.13	.24	.06	.15	-.14	.21
Consequences	.43*	.54***	.10	.34	.17	.41*
Cure/Control	.08	-.04	.13	.02	.13	-.07

	SDQ scale					
Belief concordance	TDS	CP	H	ES	PP	PSB
Illness Identity	-.05	-.20	-.06	.03	.15	-.20
Cause	.09	-.10	.37*	-.13	.13	-.11
Cause of Exacerbation	-.11	-.13	.03	-.26	.08	-.16
Time-Line	.01	.18	-.31	.22	-.10	.31
Consequences	-.48**	-.61****	-.11	-.31	-.29	-.38
Cure/Control	-.11	-.21	-.07	-.01	.01	-.22
Total concordance	-.16	-.37*	.08	-.21	.11	-.21

Note. TDS Total Difficulties; CP Conduct Problems; H Hyperactivity; ES Emotional Symptoms; PP Peer Problems; PSB Pro-social Behaviour.

Note. IPQ Illness Identity items that were concerned with affective symptoms were very similar to SDQ Emotional Symptom items.

Note. n = 31.

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.005$, **** $p < 0.001$

7.3.3 Data Analysis 3

Reasons for Achieving Good Control of Asthma

Inductive content analysis of the parents' and the children's reasons for achieving good control of asthma identified eleven domains: (i) Physical, (ii) Medical, (iii) Health Service, (iv) Medication, (v) Interpersonal, (vi) Affect, (vii) Psychological, (viii) Recreation, (ix) Education, (x) Quality of Life, and (xi) Family. Definitions of the domains and examples of representative items are presented in Table 7.14. Two independent raters coded a random selection of 200 responses that constituted approximately 20% of the responses.[1] Cohen's kappa coefficient was 0.64. Disagreements were discussed and whenever possible resolved.[2]

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[1] During the reliability analysis it became clear that the coding system contained ambiguities, and that in some instances clearer examples of the categories were required. Similarly, the responses of the participants were originally presented independently to the raters i.e., the successive responses of an individual participant were not explicitly linked in the transcripts that were provided. For this reason, much of the context of successive, linked responses was missing. To overcome these problems, four steps were taken. First, a clearer definition of ambiguous categories was provided in the coding framework. For example, 'perceptions of control' was explicitly differentiated from 'self-efficacy beliefs' and 'self-determination' i.e., making one's own choices. Second, successive, linked responses were identified as such in the reliability analysis transcripts. Third, the raters were provided with the questions that were asked of the participants. It was hoped that this would provide an additional context that would facilitate the raters' understanding of the participants' responses, and consequently, their application of the coding system. Fourth, the raters were given advice about coding within an individual response set. Specifically, they were advised that (i) a single response set may require several codes, and (ii) that a response set containing different reasons from the same domain would require the appropriate number of identical codes. For example, if a respondent reported 'missing less school and learning more', two codes of 'I' would be allocated to the response set. It was hoped that retaining information about the multifaceted aspects of several response domains, albeit numerical information in the form of a frequency count, would lead to greater external validity.

[2] The results of the reliability analysis suggested that the raters were mostly in agreement concerning the application of the coding scheme, although there was some uncertainty about the identification of discrete utterances and the salient aspects of utterances. On

Table 7.14

Reasons for achieving good control of asthma

Domain	Example
Physical	Mortality e.g., avoid death and recognition that asthma can be fatal
	Morbidity e.g., avoid illness, less severe asthma; avoid exacerbation of asthma and asthma attacks; minimise consequences of other illnesses or conditions
	Health and fitness e.g., grow; able to breathe easier; stay healthy, able to move around, feel better; recover quickly
	Longevity e.g., stay alive, live longer
Medical	Fewer contacts with medical services e.g., fewer visits to the doctor's
	Dependency and care-taking aspects of illness e.g., having to look after child
	Interdependence of asthma control, severity, and adjustment
Health Service	Resource implications for the health service
	Unpleasantness of contact with medical services
Medication	Less reliance on medication e.g., need to use inhalers less
	Negative aspects of inhalers e.g., inhalers don't taste very nice
	Negative attitudes toward and beliefs about medication e.g., taking drugs all the time isn't very good for you
Interpersonal	Likeability e.g., they're a nicer person
	Perceptions concerning social acceptance and inclusion e.g., feel normal, avoid feeling left out; feel equal
	Play (including being able to join in)
	Relationships with other children and maintenance of friendships e.g., being with others, social life, making friends
	Positive aspects of friendship and sharing activities e.g., opportunities to develop social skills, opportunities to develop as a person
	Concern and consideration for others e.g., helping others, being dependable, avoid discrimination against others, value others
	Companionship
	Avoidance of socially constructed, negative, emotional states and problems e.g., avoid embarrassment, avoid child being picked on
	Less interference with social activities
	Negative perceptions of and behaviour toward child with asthma e.g., people can think you're a freak and move away from you
	Recognition from peer group

Table 7.14 contd.

Reasons for achieving good control of asthma

Domain	Example	
Affect	Perceived unpleasantness of physical and emotional states	
	Less worry	
	Less stress	
	Minimisation of negative physical and emotional states e.g., less hurt, less physical pain; less anxious, less sad, peace of mind	
	Avoid boredom	
	Avoid feeling got on to	
	Enjoyment (of life and normal activities)	
	Happiness and contentment	
	Fun	
	Feelings of security	
	Relaxation	
	Other positive emotions e.g., love	
	Feelings concerning achievement e.g., having no regrets, feeling proud of achievements	
	Comfort	
Psychological	Beliefs	Specific beliefs about causes of illness e.g., pollution causes asthma
		Specific beliefs about consequences of asthma e.g., children with asthma are anxious
		Specific existential beliefs e.g., life is worth living, make the most of what you've got, life's about freedom of choice
		Specific individual beliefs and concerns of children
	Aspirations	Specific aspirations and wishes of child e.g., to be in the Olympics
		Specific parental hopes and wishes e.g., to be at the top of Maslow's hierarchy of needs
	Abstract Values	e.g., valuing of autonomy, self-determination
	Concrete Values	e.g., valuing of being able to do activities

Table 7.14 contd.

Reasons for achieving good control of asthma

Domain		Example
Psychological contd.		
	Positive	Self-esteem, confidence, well-being
		Perceptions of control (other than efficacy beliefs and self-determination)
		Self-efficacy e.g., feeling able to manage illness; *knowing* one is able to do thing
		Understanding and empathy e.g., understanding the situation of others
		Cognitive aspects of self-determination e.g., able to plan
	Negative	Stigma of asthma e.g., it's hard being different
		Negative aspects of feeling not in control
		Inability to cope
	General	Ability to concentrate
		Ability to cope
		Rational thinking and avoidance of negative cognitive processes e.g., reduce negative automatic thoughts such as 'I'm no good', avoid catastrophising i.e., if I don't control my asthma I'm likely to have an asthma attack and it'll happen when non-one is around and I won't be able to get help, and I'll lie on the floor for hours without being able to get help and someone will eventually come along but they won't know what to do and they'll go to phone for an ambulance but the phone won't work etc.
	Self-Perception	e.g., avoid self-labelling

Table 7.14 contd.

Reasons for achieving good control of asthma

Domain	Example
Recreation	More time (for family and) for activities
	Ability to engage in leisure activities and sport
	Variety in activities
	Endurance and non-competitive performance e.g., able to play for longer, able to run faster
	Competitive aspects of recreation e.g., performance in comparison with others, being able to challenge others and oneself, able to set targets
	Less interference with sport and other activities e.g., able to do things properly and without worrying about asthma or getting out of breath; avoid missing out on activities and occasions because of asthma
	Positive aspects of recreation e.g., exercise, avoid situations associated with a lack of variety, or restriction, in recreation
	Pets e.g., pet ownership; able to play with pets
	Monitoring of asthma management e.g., able to play without being asked about inhalers
Education	Less disruption to school attendance and schoolwork e.g., able to go to school, miss less school, able to work at school
	Education and achievement at school e.g., can get a good education and pass exams
Quality of Life	Normal life
	Day to day life easier
	Self-determination e.g., able to do what they want to do, empowerment
	Achievement and achievement of goals (including being able to concentrate on achieving goals)
	Better quality of life e.g., life's more interesting
	Choice and opportunity (experience, employment and long term prospects) e.g., broaden experience; live life to the full; choice of employment; get a good job
	Fewer restrictions e.g., enabled, able to be more spontaneous
	Able to do more (unspecified 'more')
	Ability to get on with life e.g., get on with life, live their life, keep going
	Realisation of potential and self-fulfillment
	Independence e.g., child can stay away from home for longer

Table 7.14 contd.

Reasons for achieving good control of asthma

Domain	Example
Family	Statement of family relation Valuing family and enjoyment of family activities More time for family (and for activities) Watch children and grandchildren grow "It's what any or most parents want for their children"
Other	

The coding framework was applied to the participants' responses, and for each participant, a note was made of the domains that were represented in their reasoning, and of the linkages that occurred between and within the domains. Data concerning the representation of each domain is presented in Table 7.15. The mean number of reasons for achieving good control of asthma (Parents: Mean 14.7, SD 5; Children: Mean 14.9, SD 4.6) and the mean number of linkages (Between - Parents: Mean 10.0, SD 5.9; Children: 8.5, SD 4.2; Within - Parents: Mean 3.0, SD 2.1; Children: Mean 3.1, SD 2.1) that were derived from the parents' and the children's reports did not differ significantly.

Physical, Affect, and Quality of Life domains characterised the reasoning of the parents (Table 7.15). Physical and Affect domains also characterised the reasoning of the children. The reasoning of the respondents was least often characterised by the Education, Family, Health Service, Medication and Medical domains.

In comparison with the reasoning of the children, Quality of Life was significantly more likely to characterise the reasoning of the parents (McNemar test, using binomial distribution, $p < 0.005$). Although, in comparison with the parents, a higher proportion of the children talked about Recreation and Interpersonal reasons for achieving good control of asthma, the differences were not statistically significant.

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a methodological note, this problem seemed to be mainly due to the recording of multiple reasons on a single response card. This may have been avoided by carefully explaining to the respondents that only one reason was to be recorded on each response card, and by implementing this restriction during data recording.

Table 7.15

Reasons for Achieving Good Control of Asthma by Respondent Group

Reason	Parents	Children
Physical	28 (90.3)	29 (93.5)
Medical	5 (16.1)	4 (12.9)
Health Service	0 (0.0)	0 (0.0)
Medication	5 (16.1)	4 (12.9)
Social	16 (51.8)	22 (71.0)
Affect	29 (93.5)	29 (93.5)
Psychological	21 (67.7)	20 (64.5)
Recreation	17 (54.8)	24 (77.4)
Education	7 (22.6)	10 (32.3)
Quality of life	30 (96.8)	21 (67.7)***
Family	7 (22.6)	1 (3.2)
Other	17 (54.8)	13 (41.9)

Note. Percentages are presented in parentheses.

Note. n = 31.

*** $p < 0.005$

The nature and the extent of the links between reasons for achieving good control of asthma were further examined by constructing what Bagozzi and Edwards (1998) termed "implication matrices". These illustrate how often one reason leads to another in the reports of the respondents. Table 7.16 and Table 7.17 represent the implication matrices that were derived from the parents' and the children's reports respectively.

In degrees represent the extent to which a reason was a target of other reasons. Out degrees represent the extent to which a reason was a source of links that led to other reasons. On the basis of the in degrees and the out degrees values, the nature of the respondents' motivational system i.e., their reported reasons for achieving good control of asthma was examined in terms of abstractness, centrality and prestige. Abstractness was computed as the ratio of in degrees to in degrees plus out degrees, centrality, as the ratio of in degrees plus out degrees to the total number of cell entries, and prestige, as the ratio of in degrees to the total number of cell entries.

The parents' most abstract reasons for achieving good control of asthma were representative of the Family, Psychological, and Affect domains (Table 7.18). 'Other' reasons, by virtue of their highly individual nature, were also highly abstract in terms of the motivation system structure. The least abstract reasons were representative of the Recreation, Physical and Medical domains. Quality of Life and Affect domains were central amongst the network of reasons. Quality of Life, Affect and Psychological domains were most often the targets of reasons for achieving good

Table 7.16

Implication Matrix Derived from Parents' Reasons for Achieving Good Control of their Child's Asthma

Abstract Ratio		Reason	1	2	3	4	5	6	7	8	9	10	11	*Out degrees*
0.27	1	Recreation		4	0	2	1	8	3	13	4	5	0	43
0.28	2	Physical	6		1	1	2	4	27	13	3	9	5	82
0.30	3	Medical	1	1		1	0	0	3	0	0	1	0	7
0.37	4	Education	0	0	0		0	3	6	0	0	2	0	17
0.47	5	Medication	0	2	0	0		0	0	0	1	1	0	8
0.49	6	Social	1	1	0	0	0		5	9	5	9	0	40
0.50	7	Quality of life	3	2	0	0	0	6		28	7	16	1	90
0.58	8	Affect	1	9	1	0	0	4	7		5	16	4	65
0.70	9	Other	1	1	0	0	0	1	1	2		4	0	13
0.70	10	Psychological	0	1	1	0	0	2	9	4	2		0	32
0.71	11	Family	0	0	0	0	0	0	0	3	1	0		4
		In degrees	16	32	3	10	7	38	89	89	31	76	10	401
		Mentions per goal	30	64	5	15	10	38	110	94	25	57	8	
		Number people mentioning goal ≥ 1	17	28	5	7	5	16	30	29	17	21	7	
		Percent	55	90	16	23	16	52	97	94	55	68	23	

Note. n = 31

Note. Within category links were excluded from the implication matrix to facilitate interpretation.

Note. 'Aspects of the Health Service', excluded from the implication matrix, was derived from the data of a participant whose data were excluded from the analysis.

Table 7.17

Implication Matrix Derived from Children's Reasons for Achieving Good Control of their Asthma

Abstract Ratio		Reason	1	2	3	4	5	6	7	8	9	10	11	*Out degrees*
0.15	1	Medication		0	2	0	3	0	1	3	1	0	0	11
0.29	2	Physical	1		8	3	3	2	7	19	5	5	0	69
0.35	3	Recreation	0	8		0	0	6	6	17	2	10	0	69
0.38	4	Medical	0	0	0		3	0	0	1	0	1	0	5
0.51	5	Education	0	0	0	0		2	7	2	0	1	0	17
0.53	6	Other	0	1	1	0	0		4	9	2	2	0	24
0.59	7	Quality of life	0	0	1	0	0	1		15	6	5	0	37
0.59	8	Affect	0	3	2	0	1	8	12		13	11	0	70
0.60	9	Psychological	0	0	3	0	3	2	5	3		3	0	20
0.61	10	Social	0	0	0	0	0	1	2	13	0		1	36
1.00	11	Family	0	0	0	0	0	0	0	0	0	0		0
		In degrees	2	28	37	3	18	27	53	102	30	57	1	358
		Mentions per goal	11	73	72	5	18	29	57	110	30	57	1	
		Number people mentioning goal ≥ 1	7	29	24	4	10	13	21	29	20	22	1	
		Percent	23	94	77	13	32	42	68	94	65	71	3	

Note. n = 31

Note. Within category links were excluded from the implication matrix to facilitate interpretation.

Note. 'Aspects of the Health Service', excluded from the implication matrix, was derived from the data of a participant whose data were excluded from the analysis.

Table 7.18

Parents' Reasons for Achieving Good Control of their Child's Asthma: Abstractness, Centrality and Prestige

Reason	Abstractness	Centrality	Prestige
Recreation	.27	.15	.04
Physical	.28	.28	.08
Medical	.30	.02	.01
Education	.37	.07	.02
Medication	.47	.04	.02
Social	.49	.19	.09
Quality of life	.50	.45	.22
Affect	.58	.38	.22
Other	.70	.11	.08
Psychological	.70	.27	.19
Family	.71	.03	.02

Note. n = 31

control of asthma. Medical and Medication domains were least involved in linkages with other domains.

The children's most abstract reasons for achieving good control of asthma were representative of the Family, Interpersonal, Psychological and Quality of Life domains (Table 7.19). The least abstract reasons were representative of the Medication and Physical domains. Reasons concerned with affect, and to a lesser extent, recreation, were central among the network of reasons. Affect was also most often the target of reasons for achieving good control of asthma. Family, Medical and Medication domains were least involved in linkages with other domains.

7.4 Discussion

7.4.1 Data Analysis 1

The analysis has shown that, in their spontaneous discourse about asthma, parents and children consistently referred to the prototypical components of illness representation: Identity, Cause, Time-Line, Consequences and Cure/Control. This is consistent with previous studies (Bishop et al., 1987; Goldman et al., 1991; Lau & Hartman, 1983; Weinman et al., 1996). In comparison with their parents, the children represented fewer illness representation components. The parents' and the children's cognitive representations of the child's asthma were similar with respect to the IPQ dimensions of illness representation. However, in comparison with their parents, the

Table 7.19

Children's Reasons for Achieving Good Control of their Asthma: Abstractness, Centrality and Prestige

Reason	Abstractness	Centrality	Prestige
Medication	.15	.04	.01
Physical	.29	.27	.08
Recreation	.35	.30	.10
Medical	.38	.02	.01
Education	.51	.10	.05
Other	.53	.14	.08
Quality of life	.59	.25	.15
Affect	.59	.48	.28
Psychological	.60	.14	.08
Social	.61	.26	.16
Family	1.00	.00	.00

Note. n = 31

children reported more symptoms, were more uncertain about the causes and time-line of their asthma, were less likely to agree that stress, their state of mind and contact with animals were potential triggers, and were less likely to agree that there was a lot that could be done to control their asthma. The parents' and the children's belief about a genetic predisposition to asthma was significantly associated with another individual in the household having asthma, and with the child's age at diagnosis respectively. Perceptions of less serious consequences were associated with the parents' perception that their child's asthma was well controlled, and with the children's reports of fewer symptoms. The beliefs of the parents and their child were most concordant concerning the Identity of the child's asthma.

Developmental aspects of the cognitive representation of illness, or at least its verbal representation, were suggested by the finding that, in comparison with the children, the parents represented more illness representation components in their discourse about asthma. This finding is consistent with the literature concerning the developmental shift in thinking towards abstract representation and the integration of ideas e.g., Crider (1981). However, the data are also consistent with a functionalist perspective in that the Identity, Cause of Exacerbation, and Consequences components of illness representation were represented in the discourse of the majority of the children. These aspects of the children's condition are likely to constitute the day-to-day reality of living with asthma. In contrast, 'Cause' and 'Time-Line' are likely to be more abstract aspects of asthma that are less salient to a child's experience. The salience of 'Cure/Control' is likely to vary depending on the extent of a child's self-management.

Schimdt and Weishaupt (1990) suggested that ideas about illness causality develop more slowly than ideas about symptoms and treatment. The development of illness causality concepts is likely to involve a shift in focus from external, concrete features to underlying and more abstract principles (Rosenthal et al., 1995). As already stated, a better understanding of illness causality and prevention, contingent upon this conceptual change, is likely to be a determinant of engagement in health-related behaviour, and in particular, engagement in preventative behaviour (Rosenthal et al., 1995). Spontaneous discourse about asthma, and in particular, the extent to which the Cause component features in the conversation of patients about their illness, may be a fruitful method of assessing the extent to which patients have an understanding of their disease and the rationale for its treatment.

In the present study, the concrete aspects of asthma were central to the illness representations of both the adults and the children, as demonstrated by the high proportion of respondents who spontaneously represented the Identity and the Consequences components of illness representation. This finding is consistent with the suggestion that people define their illnesses in terms of disruption of their normal routines or activities (Wilkinson, 1988). It is also consistent with the findings of Hunt et al. (1989), who reported that patients' health behaviour is situated within a context of acute symptom management. Effective, acute symptom management is likely to require accurate perception of symptoms. As such, the Identity component of asthma would be particularly salient to the children and their parents.

The extent to which the parents' and the children's IPQ cognitive representation of asthma was alike, or differed, varied according to the individual participants and the component of illness representation considered. For example, although concerning Illness Identity, there was considerable agreement between the parents and the children concerning the signs and symptoms that were associated with the child's asthma, as a group, in comparison with the parents, the children reported significantly more symptoms.

Breathlessness, wheeze and chest tightness (and from the perspective of the children, fatigue) were the most common symptoms of asthma, and this is consistent with Ayres' (1999) description of the main symptoms of asthma. The finding that, in comparison with the parents, the children reported more symptoms was likely due to the subjective nature of some of the IPQ symptoms, that in contrast to the signs of asthma, may only come to the attention of a child's parents if the child verbally reports their occurrence. An equivalent degree of Identity strength may be found only when a child consistently reports their subjective experience to their parents.

There was also a degree of agreement and disagreement amongst the parents and the children about the original causes of asthma. For example, although a similar proportion believed that pollution was a cause of asthma, in comparison with the parents, fewer children believed that heredity was a cause. This is consistent with the findings of other studies (e.g., Pradel et al., 2001) that relatively few children with asthma identified heredity as a cause of their condition. The considerable uncertainty amongst the children concerning the causes of asthma may be a reason why so few of the children referred to the Cause component of illness representation in their spontaneous reports.

Although the original IPQ makes no distinction between the proximal and the distal causes of an illness episode, with a chronic, intermittent disease such as asthma this distinction is likely to be particularly relevant to an understanding of how patients cognitively represent their illness. This is particularly important when the successful management of asthma is likely to involve environmental as well as pharmacological efforts (The British Guidelines on Asthma Management, 1997). Patients' beliefs about the causes of an exacerbation of asthma are therefore relevant to an understanding of their health-related behaviour.

The children in the present study believed that pollution and cigarette smoke were the main potential triggers of their asthma. This finding was consistent with the parents' reports, although the parents also identified pets and the child's state of mind as potential causes of an exacerbation. Of particular interest was the finding that, in comparison with the parents, the children were significantly less likely to report their mental state or the experience of stress as a cause of an exacerbation of asthma. Although the relative contribution of physical and emotional factors in precipitating an exacerbation of asthma may vary from patient to patient, it remains unclear in the present study whether the study group children were unaware of the relevance of these psychological factors or whether the parents, for whatever reason, were more prepared to express the belief that psychological factors were important as causes of an exacerbation. It may be that adaptive coping with stress and a balanced mental state are desirable aims for any individual, and the promotion of a link between asthma and these factors may represent an opportunity for a child's parents to rationalise and encourage the achievement of these desired states independently of any objective link.

Amongst several of the families, the children were involved in negotiations with their parents concerning pet ownership. In these circumstances, and given that in many instances the interview with the child was conducted in the presence of the parents, for the child to acknowledge that pets were a potential cause of an exacerbation of asthma would have considerably weakened their negotiating position. This may explain why, in comparison with their parents, the children were less likely to report that pets were a potential cause of an exacerbation. Although the vast majority of the respondents expressed a belief that exposure to cigarette smoke was detrimental to the child's state of health, only just under a half of the households were non-smoking. This is consistent with other studies and the finding that only a minority of parents were prepared to give up smoking for the sake of their child's health e.g., Donnelly et al. (1987).

In comparison with the parents, for whom a greater proportion reported that their child's asthma was a serious condition and that asthma generally can be a serious disease, a greater proportion of the children believed that asthma in general, and their asthma specifically, was not serious. Overall however, even when the respondents differed in their beliefs concerning the seriousness of the child's asthma, most were in agreement that the consequences of the child's asthma were not serious. That in comparison with the parents, a significantly greater proportion of the children reported that their asthma had "a big effect on things they could do" may have been an artefact of the questionnaire format. The equivalent IPQ-P item was "my child's asthma has had major consequences on their life". Although both items assessed the perceived consequences of the child's asthma, the wording of the IPQ-C item may have cued the children to respond concerning activity limitations, whereas the IPQ-P item was much more general. An inability to participate in sports to the same extent as their friends, for example, may have constituted a serious and major consequence for some of the children. From the parents' perspective, 'major consequences' may have been interpreted as hospitalisation.

It is noteworthy that just under half of the children in the present study expressed uncertainty concerning the controllability of their asthma, and in particular, concerning the options that were available to them to effectively manage their condition, and the role of their state of mind. However, the majority of the children believed that their treatment was effective in controlling their symptoms, and that what they did could determine whether their asthma got better or worse. This finding suggests that the majority of the children have a sense of self-determination concerning their state of health but that a considerable proportion are unsure about what they can do to control their disease other than take medication. Asthma education programmes, in addition to explaining the rationale for treatment and encouraging adherence, may serve children with asthma well by including information and advice concerning non-pharmacological management strategies.

In comparison with the children, the parents perceived their child's asthma to be more controllable. This finding may be due to the parents' greater awareness of the environmental strategies that may improve the control of the child's asthma. That most of the children in the present study were at an age when it is likely that they were assuming greater self-responsibility for the management of their condition (and many of the parents reported that their child was already sensible enough to manage their own asthma), it is of concern that their perceptions of the controllability of asthma were not more positive. Perceptions of controllability are likely to be associated with better adjustment, and in the present study, the parents' perceptions of disease control, and the children's reports of fewer symptoms, were significantly associated with their perception of less serious consequences. Analysis 2 considered this matter in greater detail and tested for significant associations between beliefs about asthma, including Cure/Control beliefs and perceived control of asthma, and the psychological well-being of a group of children with asthma.

The parents' and the children's beliefs about a genetic predisposition toward asthma were significantly associated with another member of the household having asthma and with the child's age at diagnosis respectively. When only one individual in a household suffers from asthma it may be difficult for family members to reconcile their family circumstances with the view that there is a genetic component to asthma. Older children's better understanding of illness causality and other abstract aspects of disease (Rosenthal et al., 1995; Schmidt & Weishaupt, 1990), and the recommendation that health professionals tailor the provision of disease information to a child's developmental level (Rushforth, 1999; Whitt, Dykstra & Taylor, 1979) may together explain the finding that age at diagnosis was significantly associated with the children's beliefs about heredity as a cause of asthma.

The beliefs of the parents and their child were most concordant concerning the 'Identity' of the child's asthma. In the context of family life, the most salient aspects of asthma are likely to be the child's symptoms, their precipitants and their consequences. Ideas about symptoms feature early in the representations about disease of children (Campbell, 1975; Paterson et al., 1999; Schmidt & Weishaupt, 1990), and children's descriptions of their symptoms are learned from their caregivers (Mechanic, 1964; Wilkinson, 1988). Although there was a significant association between the parents' and their child's belief that contact with animals was a potential precipitant of asthma, uncertainty on the part of the child about the potential precipitating influence of stress and the child's state of mind may explain the overall low concordance in the beliefs of the parents and their child about the triggers of asthma. Differences in the parents' and the children's interpretations of the seriousness of the child's asthma and its consequences may explain the low concordance in the beliefs of the parents and their child about the consequences of the child's condition.

In conclusion, the findings of the present analysis suggest that adults and children conceptualise asthma in terms of the illness representation components of Identity, Cause, Cause of Exacerbation, Time-Line, Consequences and Cure/Control. Similarities and differences in the verbal and cognitive representations of asthma are suggested to be a function of cognitive development, the relevance of different illness representation components to a family's day-to-day routine and the extent to which children make their parents aware of the subjective aspects of their experience.

7.4.2 Data Analysis 2

The second analysis has shown that, although a proportion of children with asthma experienced psychological difficulties, as a group, they functioned within the normal range on the SDQ measure of psychological functioning. This is consistent with previous studies (Kashani et al., 1988; Nassau & Drotar, 1995; Wamboldt et al., 1998). Although psychological difficulties were associated with beliefs about the child's asthma, and in particular with a perception of serious consequences, parent factors were also a significant predictor of the children's parent-reported difficulties.

Shared beliefs about the consequences of the child's asthma were associated with a lower incidence of the children's self-reported difficulties.

In the present study, perceptions of the seriousness of the child's asthma were associated with reports of the child's psychological difficulties, which is consistent with previous work (Hampson et al., 1994). It is likely that less serious asthma, or less serious consequences, real or perceived, leads to less disruption to normal routines and activities, which, consequently, is likely to be associated with less disease-related conflict and stress. The parents' perception of the consequences of their child's asthma was associated with their rating of the child's peer relationship difficulties. It has been speculated that parents' perception of restrictions on their child as a consequence of chronic childhood disease was associated with the parents' report of their child's poor adjustment, particularly in the domain of peer relationships (Eiser et al., 1992), and these findings support this idea.

The children's belief in heredity as a cause of their asthma was significantly associated with their self-reported peer problems. Although a confounding variable may be responsible for this finding, a belief in the aetiological significance of heredity may influence the child's self-perception, or their perception of the extent to which the disease, and, in certain extremes, other aspects of their lives, are controllable. These cognitive variables may subsequently influence the child's interaction and perception of interaction with peers. For example, a child's belief that they can do nothing about having asthma, that "it's all in the genes", may be associated with low self-esteem. In this context, peers' reaction to the child's inhaler use during team sports, for example, may further undermine the child's self-perception, impact upon the quality of their interaction with peers and lead to non-adherence with medication.

It has been suggested that parent factors may be potential determinants of children's (parent-reported) difficulties (Bender & Klinnert, 1998). In this study, factors such as number of household smokers and single parent family status were significantly positively associated with the parents' report of their child's peer problems and the impact of their child's psychological difficulties. Given the disparity between the reports of the parents and the children concerning the child's peer relationship difficulties, it is not clear whether the children genuinely experienced peer relationship difficulties, or whether the parents' reports were determined by the parents' circumstances and perceptions. In particular, the length of time before diagnosis that the parents were aware of their child's asthma-related difficulties was a highly significant predictor of the parents' reports of their child's peer relationship difficulties and the impact of their child's psychological difficulties. Horner (1997) described how the pre-diagnosis period was especially distressing for a group of mothers of children with asthma. A long period of undiagnosed and untreated childhood asthma may cause disruption of the child's daily routines and activities, which may have led to the difficulties that the parents reported. The question remains as to why the children did not report similar adjustment difficulties, although it may be that, in comparison with the parents, the children were less prepared to report difficulties with their peer relationships, perhaps because of a primary concern with the presentation of a socially successful self.

Whereas the parents' perceptions of the consequences of their child's asthma were predictive of their reports of their child's psychological difficulties, the extent to which the parents and the child shared beliefs concerning the seriousness of the child's asthma was significantly negatively associated with the child's self-reported conduct problems. This may be due to the conflict that may develop when there is a mismatch between the parents' and the child's beliefs concerning the consequences of the child's disease. Perception of high seriousness, from the point of view of a parent, in the context of a child's perception of low seriousness, may be associated with restrictions and overprotective behaviour that are perceived as unnecessary by the child (or conversely with children's behaviour that is perceived as risky from the point of view of the parent). Similarly, perception of low seriousness, from the point of view of a parent, in the context of a child's perception of high seriousness, may be associated with a belief that the child is attempting to manipulate their environment (and from the child's point of view, perception of an uncaring parent). These situations are likely to be associated with stressful family interaction. The effects of these negative exchanges may become manifest in the child's externalising difficulties. In contrast, when there is a match between the perception of the parents and their child concerning the seriousness of the child's disease, conflict concerning the child's disease and disease-related situations is less likely, and the children, as appropriate, may feel either supported and understood, or unrestricted in their activities and routine. In such situations of support and understanding, or freedom from restriction, it is likely that the children will demonstrate a good behavioural adjustment.

In conclusion, it is suggested that, within a family, concordant beliefs about a child's asthma develop through an accurate perception of the child's disease-related circumstances and/or through open discussion about the child's disease. Belief concordance may be associated with less conflict within the family concerning the child's disease, and with the child's perception of family support and understanding. In this respect, belief concordance may be a distal determinant of children's psychological well-being that operates through its impact on family interaction and the child's perceptions. The implications are that parents of children with a chronic disease are encouraged to openly discuss the child's disease with the child to facilitate the development of concordant beliefs. A reduction in disease-related conflict within the family, and a complementary increase in the child's perception of family support and understanding, may have further beneficial effects in other areas of family functioning.

7.4.3 Data Analysis 3

The analysis has shown that the participants' reasoning about achieving the goals of asthma management was related to the domains of physical health, interpersonal relationships, emotional regulation and affect, psychological functioning and well-being, recreation, education and quality of life. These domains are generally consistent with the content of asthma-specific quality of life instruments that have been designed for use with children e.g., Childhood Asthma Questionnaires (French & Christie, 1996) and the Asthma Quality of Life Questionnaire (Juniper et al., 1993). The parents and the children's reasons for achieving good control of asthma were similar in terms of their content and the proportion of respondents who expressed reasons that were representative of a domain. However, in comparison with the children, the parents were significantly more likely to represent the Quality of Life domain. The Quality of Life, Affect and Psychological domains constituted the core of the parents' motivation system. The Affect and Recreation domains constituted the core of the children's motivation system.

The analysis has shown that, from the perspective of a parent, concerns about their child's physical symptoms, restriction or interference with the child's activities, and the burden of seeking medical assistance represent concrete reasons for achieving good control of asthma. From the perspective of a child, the physical symptoms of asthma and the unpleasant aspects of its treatment e.g., the taste of inhalers, are concrete reasons for achieving good control of their condition. These findings are consistent with those of other studies (Action Asthma, 1993; Paterson & Britten, 2000; Pradel et al., 2001).

At a more abstract level, the parents and the children believed that achieving good control of asthma was important because it presented less disruption to family activities and was associated with positive affect, self-esteem, social integration, opportunities in the future and self-determination. The participants' representation of low abstract level (Physical) and high abstract level (Quality of Life, Affect, Psychological) reasons for achieving good control of asthma is consistent with Leventhal et al.'s (1984) model of a parallel system of physical and emotional regulation (see chapter 2).

Emotional regulation and positive affect were central components of the children's motivation system, and although the parents' reports suggested that these factors also were highly salient motivators from the parents' perspective, quality of life had greater centrality in the motivation system of the parents. The findings suggested that, although many of the children did refer to quality of life reasons for achieving good control of asthma, they had yet to integrate this domain into their motivation system. In contrast, the parents' holistic perspective included the long-term benefits of choice, opportunity and prospects. Consistent with this hypothesis, the children's most prestigious reason for achieving good control of asthma (the reason that was most often the target of other reasons) was 'Affect', whereas for the parents, 'Quality of Life' and 'Affect' were the most prestigious motivators.

These findings demonstrate that, although the content of the parents' and the children's motivation system were similar, an examination of their organisation revealed clear differences in the motivational utility of the respondents' reasons.

In conclusion, it is suggested that, when practitioners intervene to improve a patient's adherence with their treatment recommendations, an emphasis on the physical, recreational, affective and social benefits of achieving good control of asthma is likely to have the greatest impact on children with mild to moderate asthma. In contrast, a focus on the affective, quality of life and psychological benefits is likely to be effective when a child's parents are involved.

7.5 Summary

To improve our understanding of different aspects of childhood asthma, interviews were conducted with thirty-seven 10-11-year-old children with asthma and their parents. The interview procedure involved open-ended questions about the child's asthma, modified versions of the asthma-specific Illness Perception Questionnaire (Weinman et al., 1996), the extended version of the Strengths and Difficulties Questionnaire (Goodman, 1997; 1999; Goodman et al., 1998), and a cognitive task to determine the participants' reasons for achieving good control of asthma.

Prototypical illness representation components were identified in the parents' and the children's discourse about the child's asthma. Although, in comparison with the parents' responses to the open-ended questions, the children's responses suggested a less sophisticated cognitive representation of asthma, in response to the modified versions of the asthma-specific IPQ, the parents' and the children's responses were relatively consistent. In particular, the beliefs of the parents and their child about the signs and symptoms of the child's asthma were reasonably concordant. However, in comparison with the parents, the children reported more symptoms, expressed greater uncertainty about the causes and the time-line of asthma, were less likely to agree about the potential precipitating influence of stress and their state of mind, and were less likely to agree that there was a lot that they could do to control their symptoms.

Mean SDQ scores were within the normal range. The main difficulties reported for the individual children varied as a function of the source of information. Beliefs about the consequences of asthma were associated with the children's parent- and self-reported psychological difficulties. The children's belief that heredity was a cause of asthma was associated with their self-reported psychological difficulties. Belief concordance was associated with good psychological adjustment, especially with respect to the children's self-reports. In contrast, with respect to the children's parent-reported difficulties, demographic factors and illness characteristics were of greater significance.

Content analysis of the participants' reasons for achieving good control of asthma suggested eleven domains of intrusion: (i) Physical, (ii) Contact with Medical Services, (iii) Aspects of the Health Service, (iv) Medication, (v) Interpersonal, (vi) Affect, (vii) Psychological Functioning and Psychological Well-Being, (viii) Recreation, (ix) Education, (x) Quality of Life, and (xi) Family. Although the nature and frequency of occurrence of the parents' and the children's reasons for achieving good control of asthma were similar, there were clear differences with respect to the organisation of the parents' and the children's motivation system.

It was concluded that the similarities and differences in the beliefs of the parents and the children were a function of cognitive development, the salience of different illness representation components to a family's day-to-day routine, and the extent to which a child talked with their parents about their subjective experience of asthma. Concordant beliefs about a child's asthma were suggested to be associated with less conflict within the family concerning the child's disease, and with the child's perceptions of family support and understanding. It was suggested that an emphasis of the relevant domains of asthma intrusiveness would be most likely to encourage the initiation and maintenance of effective asthma management behaviour.

Chapter 8

Study 4

8.1 Introduction

To improve our understanding of how disease severity is associated with the different aspects of childhood asthma that were considered in study 3, children with different degrees of asthma severity (and their parents) were recruited to the present study that was concerned with the same three outcome variables: (i) cognitive representations of asthma, (ii) psychological well-being, and (iii) reasons for achieving good control of asthma. A fourth analysis considered how disease severity, parental sensitivity to their child's internal states and family discussion about asthma were associated with children's awareness and description of respiratory sensations.

With respect to the cognitive representation of asthma, it was hypothesised that, in comparison with a severe asthma group, children with mild asthma would have a weaker Identity belief (report fewer symptoms), and perceive their asthma to have less serious consequences and to be more controllable.

The second analysis involved clarification of some of the outstanding issues with respect to the literature on the psychological well-being of children with asthma. Although it has been suggested that children with asthma as a group do not differ from normative and physically healthy control groups (Kashani et al., 1988;

Nassau & Drotar, 1995; Peckham & Butler, 1978; Wamboldt et al., 1998), children with severe asthma may suffer from psychological difficulties related to their illness, its consequences and/or its treatment (Graham et al., 1967; McNichol et al., 1973; Peckham & Butler, 1978; Wamboldt et al., 1998). However, an association between asthmatic children's psychological difficulties and disease severity is not unequivocal (e.g., Kashani et al., 1988; Nassau & Drotar, 1995; Norrish et al., 1977; Wamboldt et al., 1998) and other factors, for example, the source of information about a child's difficulties, may be relevant (see chapter 3).

Some authors, who reported that children's psychological difficulties were independent of asthma severity (e.g., Norrish et al., 1977), reported an association between control of asthma and children's psychological well-being. In study 3, although reports of fewer symptoms were associated with good psychological adjustment, 'Cure/Control' beliefs were statistically independent of the child's self- or other-reported psychological well-being. However, at the time of interview, all the children were reported to have well-controlled asthma and most were at Step 1 or Step 2 of treatment according to the British Guidelines on Asthma Management (1997). Beliefs about the controllability of asthma may be of greater predictive utility when there is a wider range of disease severity among the sample, or when there is a wider range of perceived control.

The third analysis was concerned with reasons for achieving good control of asthma. It was hypothesised that, because of the potential impact of severe asthma, in comparison with mild asthma, severe asthma would be associated with a greater number of reasons for achieving good control of asthma. An additional aim was to test the reliability of the findings from study 3 that may have been an artefact of the study design i.e., responses may have been prompted by the provision of a worked-through example.

The aim of the fourth analysis was to test the hypotheses that disease severity, parental sensitivity to their child's internal states and family discussion about asthma were associated with the quality of a child's description of what out of breath feels like. Qualitative differences in children's descriptions of breathlessness have been demonstrated (see study 1 and study 2). Qualitative variability occurred both within and between the group of physically healthy children and the group of children with asthma. Although the findings were explained in terms of age effects and experience of asthma, it was suggested that family discussion about the child's asthma may also have been associated with the more detailed descriptions of breathlessness that were provided by some of the children. However, in the previous studies, no details were obtained about the severity of a child's asthma.

If negative affect leads to family discussion of internal states (Dunn & Brown, 1994), and exacerbation of asthma is associated with negative affect (Taitel et al., 1998), it is possible that the children with the most severe asthma provided the most detailed descriptions of what out of breath feels like. In a family where asthma is openly discussed there may be a greater degree of concordance between the beliefs of the parents and their child concerning asthma. Concordance between the beliefs of the parents and their child concerning the Identity (signs and symptoms) of the child's asthma is likely to indicate parental sensitivity to their child's internal states.

8.2 Method

8.2.1 Participants

Although psychological difficulties may be associated with childhood asthma (Wamboldt et al., 1998) there is no published study that has used the Strengths and Difficulties Questionnaire (Goodman, 1997; 1999; Goodman et al., 1998) to explore associations between children's psychological well-being and asthma severity. Goodman et al. (1998) reported a difference in mean score of 7.2 between a psychiatric clinic group and a community group. The difference between the samples was halved as a sensible estimation of a clinically meaningful difference in mean score between children with mild asthma and children with severe asthma. A mean score difference of this magnitude would enable the differentiation of children with a Total Difficulties Score in the abnormal, borderline and normal range. A sample size of 78 would provide the study with an 80% power to detect this difference between the two groups at the 5% level.

Participants were recruited through a Midlands hospital and through primary care practices in Birmingham, Coventry and Warwickshire. Out-patient letters and patient databases were searched for 10-13-year-old children with a diagnosis of asthma for at least one year, and who were in receipt of prescription for the control of asthma. The lists were screened to exclude patients with any serious disease, and to identify any cases where an invitation to participate in the research may have been inappropriate. Participating practices were asked to forward postage-paid project information packs with a covering letter in support of the research from the patient's doctor. Parents/guardians who were willing to participate were asked to return a contact form in a reply-paid envelope.

8.2.2 Instruments

The study instruments (Awareness of respiratory sensations; Belief concordance; Demographic and clinical information; Disease severity; Family discussion about asthma; Illness Perception Questionnaire; Parental sensitivity to their child's internal state; Reasons for achieving good control of asthma; Semi-structured interview; Sophistication of verbal representation of asthma; Strengths and Difficulties Questionnaire) are described in chapter 4.

8.2.3 Procedure

The parents and the children were asked to give written informed consent and assent respectively, either prior to or at the time of interview. Individual interviews lasted between a half and one hour. The interviews were conducted at the participants' home. Each began with the four open-ended questions that constituted the semi-structured interview. Participants' responses were recorded verbatim at the time of interview. The IPQ was then worked through with the participant(s). After having completed the Identity section of the IPQ-C (which includes reference to feeling out of breath), the children were asked to describe what out of breath feels like. The participants and the interviewer than worked through the SDQ. During the last stage of the interview the participants' reasons for achieving good control of asthma were elicited. Interviews with the parent preceded the interview with the child in all but a few instances.

8.2.4 Data Analysis 1

Data from the semi-structured interview were analysed using a pre-determined framework that corresponded to the six components of the cognitive representation of asthma. Chi-square tests or their exact-probability equivalents were used to examine differences between severity groups. Group differences in the degree of sophistication of the participants' verbal representation of asthma were examined using an independent samples t-test.

Chi-square tests or their exact probability equivalents, and independent samples t-tests were used to analyse the data from the Illness Perception Questionnaire.

8.2.5 Data Analysis 2

Independent samples t-tests were used to assess group differences on the SDQ measure. Regression analysis was used to examine the predictability of psychosocial difficulties on the basis of demographic and illness variables, components of illness representation, and belief concordance.

8.2.6 Data Analysis 3

The participants' reasons for achieving good control of asthma were analysed using the coding framework derived from the inductive content analysis of study 3 (see page 152). Chi-square tests or their exact-probability equivalents, and independent samples t-tests were used to examine group differences.

8.2.7 Data Analysis 4

Correlation analysis was used to test for significant associations at the $p < 0.01$ level.

The study was granted approval by the Local Research and Ethics Committees of East Birmingham, Coventry and Warwickshire.

8.3 Results

Forty-five of 190 (23.7%) primary care practices agreed to distribute information about the research. In comparison with the schools that were involved in study 2, the primary care practices were significantly less likely to help with patient recruitment ($\chi 2(1) = 46.9$, $p < 0.001$). Practice postcode underprivileged area score and the number of partners in a practice were not significantly correlated with study participation. The single-most common reason for non-participation that was given by the primary care practices was the practice workload at the time of the study.

Fifty-five hospital out-patients and 716 primary care patients were identified. Parental consent was given for 8 out-patients and 58 primary care patients, a response rate of 14.5% and 8% respectively.[1] Of these 66 children, 12 were excluded because they did not meet the study inclusion criteria. One family, who initially gave consent, was unable to take part in the study because of family circumstances.

In total, interviews were conducted with 25 boys (47.2%), 28 girls (52.8%), 51 mothers and 12 fathers. Conjoint interviews were conducted with 10 couples. Data from these interviews were each treated as a single data set for the purpose of analysis. The demographic characteristics of the families and the clinical characteristics of the children with asthma are presented in Table 8.1 and 8.2 respectively. In all instances, the parents who participated were the primary caregivers for the child.

8.3.1 Data Analysis 1

Semi-structured Interview

The participants' response to an open-ended request for information about the child's asthma was coded for the occurrence of discourse corresponding to the six components of illness representation: (i) Identity, (ii) Cause, (iii) Cause of

[1] Patient recruitment from participating practices tended to be negatively associated with underprivileged area score i.e., less deprivation was associated with a higher response rate, although this association was not statistically significant.

Table 8.1

Demographic Characteristics of the Mild and Severe Samples

	Mild			Severe		
	Mean	(SD)	Range	Mean	(SD)	Range
Age of parent (years)	39.0	(4.3)	29 - 46	39.2	(3.7)	33 - 45
Age of child (years.months)	11.7	(0.8)	10.2 - 13.2	11.9	(0.9)	10.4 - 13.0
Duration of asthma (years.months)	7.11	(2.8)	1.0 - 12.1	8.8	(2.7)	2.7 - 10.11
Jarman Underpriviliged Area Score[a]	3.7	(18.3)	-26.7 - 59.5	5.3	(23.9)	-26.7 - 53.1

	Mild n	Mild %	Severe n	Severe %
Sex of parent				
Male	7	15.0	5	29.0
Female	39	85.0	12	71.0
Sex of child				
Male	16	40.0	9	69.2
Female	24	60.0	4	30.8
Marital status				
Married or cohabiting	33	83.0	11	84.6
Single parent household	7	17.0	2	15.4
Number of children in household				
1	8	20.0	2	15.4
2	15	38.0	6	46.2
3	14	35.0	3	23.1
4	2	5.0	2	15.4
≥ 5	1	3.0	0	0.0
Number of smokers in household				
0	21	53.0	7	53.8
1	14	35.0	19	35.8
2	5	13.0	6	11.3

[a] The mean and standard deviation of the distribution of ward scores in England and Wales reported by Jarman (1984) were 0 and 16.0 respectively. Higher scores are associated with social indicators of underprivilege.

Table 8.2

Clinical and Historical Characteristics of the Mild and Severe Samples

	Mild		Severe	
	n	%	n	%
Other with a history of asthma living in the household				
No	16	40.0	5	38.5
Yes	24	60.0	8	61.5
Age at diagnosis (years)[a]				
Younger than or equal to 3	21	53.0	8	61.5
Between 3 and 5	7	18.0	3	23.1
Older than 5	11	28.0	2	15.4
Step of treatment[b]				
Step 1	5	12.5		
Step 2	35	87.5		
Step 3			9	69.2
Step 4 and beyond			4	30.8
Perceived control of asthma				
1 Very poorly controlled	0	0.0	0	0.0
2	2	5.0	0	0.0
3	0	0.0	1	7.7
4	3	8.0	2	15.4
5	9	23.0	3	23.1
6	14	35.0	3	23.1
7 Very well controlled	11	28.0	4	30.8

[a] Data from one participant was excluded because of uncertainty about when precisely the child was diagnosed as having asthma. [b] Step of treatment was determined by a respiratory paediatrician, blind to the responses of the participants. [c] Data from one participant was excluded because they were unwilling to rate perceived control of asthma, given their doubt about the child's diagnosis of asthma.

Exacerbation, (iv) Time-Line, (v) Consequences, and (vi) Cure/Control. Two independent raters coded a random selection of ten interview transcripts. Although concerning three of forty-one passages of text there was a disagreement about the passages' eligibility for coding, Cohen's kappa coefficient for the remaining 38 segments was 1.00. Disagreements were discussed and whenever possible resolved.

Mild and severe groups did not differ significantly in the proportion of illness representation components that were represented (Table 8.3). The sophistication of the verbal representations of the mild and severe groups did not differ significantly (Mild: Parents, Mean = 4.18, SD 0.93; Children, Mean = 2.85, SD 1.03; Severe: Parents, Mean = 4.31, SD 1.11; Children, Mean = 2.92, SD 0.76). The sophistication of the children's verbal representation was independent of any demographic factor or illness characteristic.

Illness Perception Questionnaire

IPQ-P

The proportion of parents who identified each of the signs and symptoms that were associated with their child's asthma did not differ significantly between the severity groups (Table 8.4). Similarly, the mild and the severe group did not differ significantly in the number of reported signs and symptoms (Identity) (Mild: Mean = 10.2, SD 3.3; Severe: Mean = 11.1, SD 4.0) (t (51) = -0.84, ns). Although, in comparison with the mild group parents, the parents of children with

Table 8.3

Number of Spontaneous Verbal Representations of IPQ Components by Asthma Severity and Respondent

	Parents	
IPQ component	Mild[a]	Severe[b]
Identity	31 (77.5)	11 (84.6)
Cause	11 (27.5)	5 (38.5)
Exacerbation	35 (87.5)	11 (84.6)
Time-Line	28 (70.0)	9 (69.2)
Consequences	33 (82.5)	10 (76.9)
Cure/Control	29 (72.5)	10 (76.9)
	Children	
IPQ component	Mild[a]	Severe[b]
Identity	27 (67.5)	11 (84.6)
Cause	2 (5.0)	1 (7.7)
Exacerbation	31 (77.5)	10 (76.9)
Time-Line	14 (35.0)	6 (46.2)
Consequences	31 (77.5)	8 (61.5)
Cure/Control	9 (22.5)	2 (15.4)

Note. Percentages are presented in parentheses.

[a] n = 40. [b] n = 13.

Table 8.4

Parents' Cognitive Representation of Asthma Identity by Asthma Severity

	Parents	
Identity component	Mild[a]	Severe[b]
Pain	26 (65.0)	9 (69.2)
Nausea	18 (45.0)	6 (46.2)
Breathlessness	39 (97.5)	13 (100.0)
Weight gain	5 (12.5)	2 (15.4)
Fatigue	31 (77.5)	12 (92.3)
Tight chest	38 (95.0)	13 (100.0)
Panic attacks	18 (45.0)	5 (38.5)
Headaches	20 (50.0)	8 (61.5)
Upset stomach	11 (27.5)	5 (38.5)
Sleep difficulties	28 (70.0)	11 (84.6)
Nervous tension	17 (42.5)	6 (46.2)
Weight loss	3 (7.5)	2 (15.4)
Spots	2 (5.0)	1 (7.7)
Sore eyes	18 (45.0)	5 (38.5)
Toothache	1 (2.5)	0 (0.0)
Anxiety	26 (65.0)	7 (53.8)
Sore throat	28 (70.0)	9 (69.2)
Wheezing	37 (92.5)	13 (100.0)
Hair falling out	1 (2.5)	0 (0.0)
Dizziness	5 (12.5)	4 (30.8)
Feeling shakey	16 (40.0)	8 (61.5)
Loss of strength	18 (45.0)	5 (38.5)

Note. Values represent the number of participants who endorsed each response option. Percentages are presented in parentheses.

[a] n = 40. [b] n = 13.

severe asthma were more uncertain about the aetiological significance of pollution (χ^2 (2) = 6.62, Fisher's Exact, $p < 0.05$), the mild and the severe group did not otherwise differ significantly in their beliefs about the causes (Table 8.5), the causes of an exacerbation (Table 8.6), or the time-line of their child's asthma (Mild: Mean = 16.3, SD 2.6; Severe: Mean = 16.9, SD 4.0) (t (51) = -0.68, ns). The parents' perception of the seriousness of asthma as a medical condition did not differ significantly as a function of severity group (χ^2 (2) = 4.01, Fisher's Exact, ns), and the mild and the severe group did not differ significantly in their perception of the seriousness of their child's asthma specifically (Mild: Mean = 16.6, SD 3.6; Severe: Mean = 17.9, SD 3.8) (t (51) = -1.1, ns). The mild and the severe group did not differ significantly in their beliefs about the controllability of their child's asthma (Mild: Mean = 22.8, SD 2.2; Severe: Mean = 22.7, SD 3.7) (t (51) = 0.07, ns).

IPQ-C

The proportion of the children who identified each of the signs and symptoms that were associated with their asthma did not differ significantly between the severity groups (Table 8.7). Similarly, the mild and the severe group did not differ significantly in the number of signs and symptoms that they reported (Identity) (Mild: Mean = 10.6, SD 4.1; Severe: Mean = 12.5, SD 3.6) (t (51) = -1.45, ns), or in their beliefs about the causes (Table 8.8), the causes of an exacerbation (Table 8.9), and the time-line of their asthma (Mild: Mean = 14.7, SD 2.8; Severe: Mean = 13.8, SD 1.9) (t (51) = 1.04, ns). In comparison with the severe group, the children with mild asthma perceived asthma generally to be less serious

Table 8.5

Parents' Cognitive Representation of the Causes of Asthma by Asthma Severity

Cause	Mild[a]					Severe[b]				
	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Germ or virus	2 (5.0)	4 (10.0)	3 (7.5)	19 (47.5)	12 (30.0)	1 (7.7)	1 (7.7)	0 (0.0)	7 (53.8)	4 (30.8)
Diet	0 (0.0)	2 (5.0)	5 (12.5)	27 (67.5)	6 (15.0)	0 (0.0)	0 (0.0)	2 (15.4)	7 (53.8)	4 (30.8)
Pollution	7 (17.5)	14 (35.0)	7 (17.5)	10 (25.0)	2 (5.0)	0 (0.0)	2 (15.4)	6 (46.2)	4 (30.8)	1 (7.7)*
Heredity	7 (17.5)	23 (57.5)	3 (7.5)	3 (7.5)	4 (10.0)	4 (30.8)	4 (30.8)	1 (7.7)	3 (23.1)	1 (7.7)
Chance	0 (0.0)	9 (22.5)	9 (22.5)	19 (47.5)	3 (7.5)	0 (0.0)	1 (7.7)	3 (23.1)	4 (30.8)	5 (38.5)
Stress	1 (2.5)	3 (7.5)	2 (5.0)	23 (57.5)	11 (27.5)	1 (7.7)	0 (0.0)	1 (7.7)	6 (46.2)	5 (38.5)
Child's behaviour	0 (0.0)	1 (2.5)	3 (7.5)	24 (60.0)	12 (30.0)	0 (0.0)	0 (0.0)	0 (0.0)	8 (61.5)	5 (38.5)
Other people's fault	0 (0.0)	4 (10.0)	1 (2.5)	20 (50.0)	15 (37.5)	0 (0.0)	0 (0.0)	0 (0.0)	6 (46.2)	7 (53.8)
Poor medical care in the past	0 (0.0)	0 (0.0)	1 (2.5)	26 (65.0)	13 (32.5)	0 (0.0)	0 (0.0)	2 (15.4)	8 (61.5)	3 (23.1)
No-one's fault	8 (20.0)	26 (65.0)	2 (5.0)	4 (10.0)	0 (0.0)	3 (23.1)	7 (53.8)	2 (15.4)	1 (7.7)	0 (0.0)
Child's state of mind	0 (0.0)	1 (2.5)	2 (5.0)	24 (60.0)	13 (32.5)	0 (0.0)	1 (7.7)	1 (7.7)	5 (38.5)	6 (46.2)

Note. Values represent the number of participants who endorsed each response option. Percentages are presented in parentheses.

[a] $n = 40$. [b] $n = 13$.

* $p < 0.05$

Table 8.6

Parents' Cognitive Representation of the Causes of an Exacerbation of Asthma by Asthma Severity

	Mild[a]					Severe[b]				
Cause	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Diet	2 (5.0)	8 (20.0)	7 (17.5)	20 (50.0)	3 (7.5)	0 (0.0)	5 (38.5)	0 (0.0)	7 (53.8)	1 (7.7)
Pollution	18 (45.0)	20 (50.0)	1 (2.5)	1 (2.5)	0 (0.0)	3 (23.1)	9 (69.2)	1 (7.7)	0 (0.0)	0 (0.0)
Chance	0 (0.0)	6 (15.0)	6 (15.0)	24 (60.0)	4 (10.0)	0 (0.0)	1 (7.7)	3 (23.1)	5 (38.5)	4 (30.8)
Stress	2 (5.0)	27 (67.5)	4 (10.0)	5 (12.5)	2 (5.0)	2 (15.4)	3 (23.1)	3 (23.1)	5 (38.5)	0 (0.0)
Being near cats or dogs	10 (25.0)	15 (37.5)	3 (7.5)	12 (30.0)	0 (0.0)	6 (46.2)	2 (15.4)	1 (7.7)	4 (30.8)	0 (0.0)
Cigarette smoke	13 (32.5)	24 (60.0)	2 (5.0)	1 (2.5)	0 (0.0)	5 (38.5)	6 (46.2)	1 (7.7)	1 (7.7)	0 (0.0)
Child's behaviour	0 (0.0)	4 (10.0)	1 (2.5)	23 (57.5)	12 (30.0)	0 (0.0)	1 (7.7)	2 (15.4)	5 (38.5)	5 (38.5)
Other people's fault	0 (0.0)	2 (5.0)	2 (5.0)	19 (47.5)	17 (42.5)	0 (0.0)	0 (0.0)	1 (7.7)	5 (38.5)	7 (53.8)
Doctors' and nurses' fault	0 (0.0)	1 (2.5)	0 (0.0)	26 (65.0)	13 (32.5)	0 (0.0)	0 (0.0)	1 (7.7)	8 (61.5)	4 (30.8)
No-one's fault	1 (2.5)	18 (45.0)	10 (25.0)	11 (27.5)	0 (0.0)	2 (15.4)	5 (38.5)	4 (30.8)	2 (15.4)	0 (0.0)
Child's state of mind	0 (0.0)	22 (55.0)	5 (12.5)	12 (30.0)	1 (2.5)	0 (0.0)	6 (46.2)	3 (23.1)	4 (30.8)	0 (0.0)

Note. Values represent the number of participants who endorsed each response option. Percentages are presented in parentheses.

[a] $n = 40$. [b] $n = 13$.

Table 8.7

Children's Cognitive Representation of Asthma Identity by Asthma Severity

	Children	
Identity component[a]	Mild[b]	Severe[c]
Pain	29 (72.5)	12 (92.3)
Nausea	18 (45.0)	6 (46.2)
Breathlessness	40 (100.0)	13 (100.0)
Weight gain	9 (22.5)	4 (30.8)
Fatigue	27 (67.5)	11 (84.6)
Tight chest	37 (92.5)	13 (100.0)
Panic attacks	18 (45.0)	5 (38.5)
Headaches	15 (37.5)	9 (69.2)
Upset stomach	9 (22.5)	5 (38.5)
Sleep difficulties	31 (77.5)	11 (84.6)
Nervous tension	21 (52.5)	8 (61.5)
Weight loss	5 (12.5)	2 (15.4)
Spots	5 (12.5)	3 (23.1)
Sore eyes	17 (42.5)	5 (38.5)
Toothache	2 (5.0)	1 (7.7)
Anxiety	21 (52.5)	10 (76.9)
Sore throat	23 (57.5)	8 (61.5)
Wheezing	36 (90.0)	13 (100.0)
Hair falling out	0 (0.0)	0 (0.0)
Dizziness	20 (50.0)	8 (61.5)
Feeling shakey	17 (42.5)	7 (53.8)
Loss of strength	24 (60.0)	8 (61.5)

Note. Values represent the number of participants who endorsed each response option. Percentages are presented in parentheses.

[a] IPQ-C version presented in Table 4.2. [b] n = 40. [c] n = 13.

Table 8.8

Children's Cognitive Representation of the Causes of Asthma by Asthma Severity

	Mild[b]					Severe[c]				
Cause[a]	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Germ or virus	2 (5.0)	5 (12.5)	11 (27.5)	17 (42.5)	5 (12.5)	1 (7.7)	2 (15.4)	4 (30.8)	5 (38.5)	1 (7.7)
Diet	2 (5.0)	1 (2.5)	6 (15.0)	17 (42.5)	14 (35.0)	0 (0.0)	0 (0.0)	1 (7.7)	6 (46.2)	6 (46.2)
Pollution	5 (12.5)	13 (32.5)	10 (25.0)	7 (17.5)	5 (12.5)	4 (30.8)	4 (30.8)	3 (23.1)	2 (15.4)	0 (0.0)
Heredity	3 (7.5)	12 (30.0)	11 (27.5)	10 (25.0)	4 (10.0)	2 (15.4)	4 (30.8)	3 (23.1)	2 (15.4)	2 (15.4)
Chance	0 (0.0)	15 (37.5)	11 (27.5)	11 (27.5)	3 (7.5)	1 (7.7)	3 (23.1)	4 (30.8)	4 (30.8)	1 (7.7)
Stress	0 (0.0)	1 (2.5)	9 (22.5)	18 (45.0)	12 (30.0)	0 (0.0)	2 (15.4)	3 (23.1)	3 (23.1)	5 (38.5)
Child's behaviour	0 (0.0)	0 (0.0)	2 (5.0)	18 (45.0)	20 (50.0)	0 (0.0)	0 (0.0)	2 (15.4)	5 (38.5)	6 (46.2)
Other people's fault	0 (0.0)	0 (0.0)	3 (7.5)	16 (40.0)	21 (52.5)	0 (0.0)	0 (0.0)	1 (7.7)	7 (53.8)	5 (38.5)
Poor medical care in the past	0 (0.0)	0 (0.0)	2 (5.0)	13 (32.5)	25 (62.5)	0 (0.0)	0 (0.0)	1 (7.7)	3 (23.1)	9 (69.2)
No-one's fault	17 (42.5)	22 (55.0)	1 (2.5)	0 (0.0)	0 (0.0)	6 (46.2)	7 (53.8)	0 (0.0)	0 (0.0)	0 (0.0)
Child's state of mind	0 (0.0)	0 (0.0)	3 (7.5)	20 (50.0)	17 (42.5)	0 (0.0)	0 (0.0)	3 (23.1)	8 (61.5)	2 (15.4)

Note. Values represent the number of participants who endorsed each response option. Percentages are presented in parentheses.

[a] IPQ-C version presented in Table 4.3. [b] n = 40. [c] n = 13.

Table 8.9

Children's Cognitive Representation of the Causes of an Exacerbation of Asthma by Asthma Severity

	Mild[b]					Severe[c]				
Cause of Exacerbation[a]	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Diet	4 (10.0)	10 (25.0)	5 (12.5)	16 (40.0)	5 (12.5)	0 (0.0)	3 (23.1)	2 (15.4)	6 (46.2)	2 (15.4)
Pollution	15 (37.5)	17 (42.5)	4 (10.0)	2 (5.0)	2 (5.0)	3 (23.1)	9 (69.2)	1 (7.7)	0 (0.0)	0 (0.0)
Chance	0 (0.0)	1 (2.5)	6 (15.0)	15 (37.5)	18 (45.0)	0 (0.0)	1 (7.7)	3 (23.1)	5 (38.5)	4 (30.8)
Stress	0 (0.0)	9 (22.5)	13 (32.5)	16 (40.0)	2 (5.0)	2 (15.4)	5 (38.5)	3 (23.1)	1 (7.7)	2 (15.4)
Being near cats or dogs	8 (20.0)	11 (27.5)	8 (20.0)	7 (17.5)	6 (15.0)	4 (30.8)	7 (53.8)	1 (7.7)	1 (7.7)	0 (0.0)
Cigarette smoke	23 (57.5)	12 (30.0)	3 (7.5)	2 (5.0)	0 (0.0)	8 (61.5)	5 (38.5)	0 (0.0)	0 (0.0)	0 (0.0)
Child's behaviour	0 (0.0)	3 (7.5)	9 (22.5)	16 (40.0)	12 (30.0)	0 (0.0)	3 (23.1)	4 (30.8)	5 (38.5)	1 (7.7)
Other people's fault	0 (0.0)	0 (0.0)	7 (17.5)	16 (40.0)	17 (42.5)	0 (0.0)	0 (0.0)	2 (15.4)	6 (46.2)	5 (38.5)
Doctors' and nurses' fault	0 (0.0)	0 (0.0)	3 (7.5)	14 (35.0)	23 (57.5)	0 (0.0)	0 (0.0)	0 (0.0)	4 (30.8)	9 (69.2)
No-one's fault	13 (32.5)	20 (50.0)	5 (12.5)	2 (5.0)	0 (0.0)	4 (30.8)	5 (38.5)	2 (15.4)	1 (7.7)	1 (7.7)
Child's state of mind	0 (0.0)	1 (2.5)	16 (40.0)	19 (47.5)	4 (10.0)	0 (0.0)	3 (23.1)	5 (38.5)	5 (38.5)	0 (0.0)

Note. Values represent the number of participants who endorsed each response option. Percentages are presented in parentheses.

[a] IPQ-C version presented in Table 4.4. [b] n = 40. [c] n = 13.

(χ^2 (2) = 7.8, Fisher's Exact, $p < 0.05$), although they did not differ significantly in their perception of the seriousness of their asthma specifically (Mild: Mean = 16.1, SD 4.3; Severe: Mean = 17.5, SD 2.6) (t (51) = -1.2, ns). Although the children's beliefs about the effectiveness of their medication in controlling the symptoms of asthma did not differ significantly as a function of severity group (χ^2 (2) = 0.68, Fisher's Exact, ns), in comparison with the mild group, the children with severe asthma were more likely to agree that there was a lot that they could do to control their symptoms (χ^2 (2) = 6.5, Fisher's Exact, $p < 0.05$).

8.3.2 Data Analysis 2

Strengths and Difficulties Questionnaire

For the mild and severe group, parent- and self-reported mean Total Difficulties scores were within the normal range, as were all sub-scale scores (Table 8.10). Children's parent-reported difficulties did not differ significantly as a function of severity group. However, in comparison with the mild group, children with severe asthma reported significantly more hyperactivity (t (51) = -2.24, $p < 0.05$). Similarly, although the proportion of cases identified from the parents' reports did not differ significantly as a function of severity group (Table 8.10), the proportion of hyperactivity cases identified from the children's reports was significantly positively associated with the severity of the child's asthma (χ^2 (1) = 5.44, Fisher's exact, $p < 0.05$).

Table 8.10

Strengths and Difficulties of Children with Asthma by Asthma Severity and Respondent

	Parents					
	Mean		Standard deviation		Number of cases[a]	
SDQ scale	Mild[b]	Severe[c]	Mild[b]	Severe[c]	Mild[b]	Severe[c]
Conduct Problems	2.08	2.15	1.97	1.57	7 (17.5)	3 (23.1)
Hyperactivity	4.00	5.38	2.87	2.66	9 (22.5)	4 (30.8)
Emotional Symptoms	3.15	2.77	2.49	2.31	13 (32.5)	2 (15.4)
Peer Problems	1.88	2.69	1.42	2.36	6 (15.0)	3 (23.1)
Pro-social Behaviour	8.75	8.54	1.56	1.66	0 (0.0)	0 (0.0)
Total Difficulties	11.10	13.00	6.13	5.43	6 (15.0)	3 (23.1)
Impact	0.65	1.85	1.14	1.95	8 (20.0)	6 (46.2)

	Children					
	Mean		Standard deviation		Number of cases[a]	
SDQ scale	Mild[b]	Severe[c]	Mild[b]	Severe[c]	Mild[b]	Severe[c]
Conduct Problems	2.90	2.69	1.63	1.55	8 (20.0)	2 (15.4)
Hyperactivity	3.95	5.62*	2.42	2.02	6 (15.0)	6 (46.2)*
Emotional Symptoms	2.85	3.77	2.18	1.59	2 (5.0)	1 (7.7)
Peer Problems	1.85	2.15	1.53	1.86	0 (0.0)	1 (7.7)
Pro-social Behaviour	7.93	7.77	1.72	1.74	1 (2.5)	0 (0.0)
Total Difficulties	11.55	14.23	5.51	4.92	2 (5.0)	2 (15.4)
Impact	0.65	0.62	1.39	0.65	8 (20.0)	1 (7.7)

[a] Values represent the number of participants who endorsed each response option. Percentages are presented in parentheses. [b] n = 40. [c] n = 13.

* $p < 0.05$

Children's Psychological Well-Being: Associations with Demographic Variables, Illness Characteristics, and Beliefs about Asthma

Demographic factors, and in particular the number of smokers who lived in the household and the sex of the child, predicted the parents' reports of their child's psychological well-being (Table 8.11). Step of treatment, as an index of disease severity, was significantly associated with the parents' reports of the impact of any psychological difficulties ($r = 0.449$; $n = 53$, $p < 0.005$). Although the parents' perception of the extent to which their child's asthma was controlled was significantly associated with the child's parent-reported psychological well-being, it did not make a significant, independent contribution to the variance in SDQ (P4-16) outcome when the number of smokers living in the household was included in the regression models.

In the mild group, although the parents' beliefs about asthma, and in particular their perception of the extent to which their child's asthma was controlled, were associated with their reports of their child's psychological well-being, demographic factors were generally more reliably associated with the SDQ (P4-16) outcome measures (Table 8.12). In contrast, in the severe group, the parents' beliefs about asthma, and in particular their beliefs about the consequences of asthma, were significantly associated with their reports of their child's psychological well-being, whereas demographic and illness variables were less strongly associated with the SDQ (P4-16) outcome measures (Table 8.13). In the mild and severe group, concordance in the beliefs of the parents and their child concerning the child's asthma (belief concordance total score) and its

Table 8.11

Correlations between the parents' beliefs about their child's asthma, demographic factors, illness characteristics and their child's parent-reported psychological well-being

	SDQ scale						
Beliefs about asthma	TDS	IS	CP	H	ES	PP	PSB
Illness Identity	.21	.35*	-.15	-.06	.44***	.37**	.23
Time-Line	.14	-.03	.23	.15	.07	-.12	-.02
Consequences	-.05	.22	-.18	-.26	.20	.19	.07
Cure/Control	-.08	-.22	.01	.14	-.12	-.34*	.15
Cause – Diet	.10	.08	.21	.09	-.07	.08	-.38**
Perceived control of asthma	-.28	-.40***	-.15	-.14	-.15	-.39**	-.01

	SDQ scale						
Demographic factor	TDS	IS	CP	H	ES	PP	PSB
Age of parent	-.43***	-.34*	-.32*	-.30	-.22	-.34*	.23
Sex of parent[a]	-.01	-.06	-.09	.02	.05	-.04	.34*
Sex of child[a]	-.39***	-.17	-.48****	-.58****	.12	-.03	.42***
Single parent household	.03	-.05	-.08	-.07	.12	.13	-.04
Number of children	.11	.12	.21	.24	-.04	-.20	.05
Number of smokers	.30*	.38**	.15	.18	.13	.39***	.10
Underprivileged area score	.05	-.04	-.11	.01	-.02	.30*	-.10

	SDQ scale						
Illness characteristic	TDS	IS	CP	H	ES	PP	PSB
Age at diagnosis	-.01	.10	.06	-.05	.08	-.10	.10
Duration of diagnosis	.03	-.06	-.04	.05	-.04	.12	-.11
Duration of pre-diagnosis awareness	-.03	-.17	.17	.04	-.09	-.23	-.09
Time since last attack	-.22	-.22	-.14	-.14	-.16	-.15	.14
Step of treatment	.15	.45***	.06	.19	-.01	.17	.03

Note. TDS Total Difficulties; IS Impact; CP Conduct Problems; H Hyperactivity; ES Emotional Symptoms; PP Peer Problems; PSB Pro-social Behaviour.

Note. n = 53.

[a] 1 = Male, 2 = Female.

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.005$, **** $p < 0.001$

Table 8.12

Correlations between the mild group parents' beliefs about their child's asthma, demographic factors, illness characteristics and their child's parent-reported psychological well-being

	SDQ scale						
Beliefs about asthma	TDS	IS	CP	H	ES	PP	PSB
Illness Identity	.03	.16	-.20	-.19	.35*	.17	.22
Time-Line	.24	.14	.24	.10	.22	.14	-.13
Consequences	-.30	-.18	-.28	-.42**	.05	-.13	.15
Cure/Control	.14	-.06	.07	.15	.15	-.07	.02
Exacerbation – Diet	.48***	.24	.35*	.31*	.37*	.31*	-.34*
Exacerbation – Child's state of mind	.38*	.27	.11	.26	.30	.43	-.12
Perceived control of asthma[a]	-.31	-.54****	-.19	-.24	-.14	-.37*	-.09
Belief concordance	-.41**	-.00	-.24	-.31	-.34*	-.24	.27

	SDQ scale						
Demographic factor	TDS	IS	CP	H	ES	PP	PSB
Age of parent	-.41**	-.30	-.33*	-.31	-.18	-.37*	.28
Sex of parent[b]	-.11	-.18	-.15	.06	-.08	-.27	.17
Sex of child[b]	-.37*	-.16	-.47***	-.52***	.07	.00	.56****
Single parent household	-.03	-.09	-.09	-.16	.11	.14	-.01
Number of children	.16	.26	.28	.24	-.00	-.18	.01
Number of smokers	.24	.46***	.11	.24	.05	.31	.09
Underprivileged area score	.05	-.08	-.04	-.02	-.04	.37*	-.06

	SDQ scale						
Illness characteristic	TDS	IS	CP	H	ES	PP	PSB
Age at diagnosis[a]	-.14	-.01	-.02	-.07	-.04	-.37*	.32*
Duration of diagnosis[a]	.15	.02	.05	.06	.08	.37*	-.32*
Duration of pre-diagnosis awareness[c]	.03	-.08	.20	.12	-.10	-.21	-.12
Time since last attack[d]	-.16	-.15	-.15	-.14	-.11	-.01	.11

Note. TDS Total Difficulties; IS Impact; CP Conduct Problems; H Hyperactivity; ES Emotional Symptoms; PP Peer Problems; PSB Pro-social Behaviour.

Note. n = 40.

[a] n = 39. [b] 1 = Male, 2 = Female. [c] n = 37. [d] n = 30.

* p < 0.05, ** p < 0.01, *** p < 0.005, **** p < 0.001

Table 8.13

Correlations between the severe group parents' beliefs about their child's asthma, demographic factors, illness characteristics and their child's parent-reported psychological well-being

	SDQ scale						
Beliefs about asthma	TDS	IS	CP	H	ES	PP	PSB
Illness Identity	.72**	.60*	-.00	.20	.77***	.67*	.29
Time-Line	-.14	-.32	.24	.25	-.26	-.51	.22
Consequences	.72**	.86****	.15	.09	.77***	.72**	-.10
Cure/Control	-.56*	-.44	-.15	.16	-.70**	-.68*	.39
Cause - Other people's fault	.03	.16	.31	.10	-.25	-.01	-.70**
Exacerbation - Diet	-.60*	-.52	-.21	.24	-.74***	-.77***	-.04
Perceived control of asthma	-.15	-.17	.04	.24	-.24	.42	.18
Belief concordance - Consequences	-.73**	-.53	-.72**	-.42	-.29	-.43	.43

	SDQ scale						
Demographic factor	TDS	IS	CP	H	ES	PP	PSB
Age of parent	-.56*	-.59*	-.24	-.33	-.39	-.38	.06
Sex of parent[a]	.34	.21	.05	.01	.39	.44	.70*
Sex of child[a]	-.38	.06	-.62*	-.69*	.22	.09	-.02
Single parent household	.25	.04	-.04	.27	.14	.15	-.14
Number of children	-.11	-.14	-.10	.23	-.18	-.27	.17
Number of smokers	.56*	.39	.32	.02	.42	.65*	.09
Underprivileged area score	.02	-.04	-.33	.05	.04	.18	-.18

	SDQ scale						
Illness characteristic	TDS	IS	CP	H	ES	PP	PSB
Age at diagnosis	.54	.47	.34	.10	.46	.47	-.58
Duration of diagnosis	-.50	-.38	-.38	-.09	-.40	-.41	.59*
Duration of pre-diagnosis awareness	-.53	-.42	-.14	-.25	-.39	-.45	-.05
Time since last attack[b]	-.52	-.51	-.04	-.08	-.52	-.63*	.32

Note. TDS Total Difficulties; IS Impact; CP Conduct Problems; H Hyperactivity; ES Emotional Symptoms; PP Peer Problems; PSB Pro-social Behaviour.

Note. n = 13.

[a] 1 = Male, 2 = Female. [b] n = 11.

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.005$, **** $p < 0.001$

consequences respectively was significantly negatively associated with the parents' report of their child's psychological difficulties ($r = -0.41$; $n = 40$, $p < 0.01$ and $r = -0.73$; $n = 13$, $p < 0.01$ respectively).

The children's beliefs about their asthma, and in particular the extent to which they associated symptoms with their asthma (Illness Identity) and their beliefs about its consequences, were significantly associated with their self-reported psychological difficulties (Table 8.14).

In the mild group, the children's beliefs about asthma, and in particular beliefs about its consequences, were significantly associated with their self-reported psychological well-being (Table 8.15). In the severe group, although the children's beliefs about asthma were also significantly associated with their self-reported psychological well-being (Table 8.16), in comparison with the mild group, the pattern of association was different. For example, Illness Identity and Consequences beliefs were independent of Total Difficulties, Emotional Symptoms and Peer Problems, Consequences beliefs were significantly negatively associated with Pro-Social Behaviour, and beliefs about the causes of asthma and attributions of blame concerning causality were associated with the children's self-reported psychological well-being. However, rather than any clear association between agreement/disagreement concerning the causes of asthma and SDQ (S11-16) outcome, the significant associations were in respect to the children's strength of belief. For this group of children, an expression of less strong agreement/disagreement tended to be associated with a better psychological adjustment. In both the mild and severe group, in comparison with the children's

Table 8.14

Correlations between the children's beliefs about their asthma, demographic factors, illness characteristics and their self-reported psychological well-being

	SDQ scale						
Beliefs about asthma	TDS	IS	CP	H	ES	PP	PSB
Illness Identity	.47****	.12	.29*	.19	.44***	.43***	-.12
Time-Line	.04	-.07	.21	.19	-.18	-.13	-.20
Consequences	.44***	.28*	.24	.19	.42***	.42***	-.17
Control - Medication	.16	-.00	.01	.00	.41***	.01	.11
Exacerbation - Pollution	-.11	-.43***	-.18	-.12	.08	-.11	.20

	SDQ scale						
Demographic factor	TDS	IS	CP	H	ES	PP	PSB
Age of parent	-.26	-.27	-.43***	-.11	-.04	-.25	.11
Age of child	.09	-.01	.00	.02	.12	.12	-.16
Sex of child[a]	-.22	-.18	-.31*	-.32*	-.00	.05	.34*
Single parent household	.00	-.03	-.08	-.01	.01	.09	.03
Number of children	.09	.12	.30*	.14	-.04	-.14	-.27
Number of smokers	.35*	.34*	.26	.30*	.08	.37**	-.17
Underprivileged area score	.29*	.10	.23	.23	.08	.31*	.01

	SDQ scale						
Illness characteristic	TDS	IS	CP	H	ES	PP	PSB
Age at diagnosis	-.01	.12	-.15	.02	.06	.01	.13
Duration of diagnosis	.04	-.13	.15	-.02	-.02	.03	-.17
Duration of pre-diagnosis awareness	-.12	-.11	-.05	.04	-.13	-.25	-.13
Time since last attack	-.26	-.25	-.02	-.25	-.17	-.21	.12
Step of treatment	.15	-.02	-.02	.18	.16	.05	-.09

Note. TDS Total Difficulties; IS Impact; CP Conduct Problems; H Hyperactivity; ES Emotional Symptoms; PP Peer Problems; PSB Pro-social Behaviour.

Note. n = 53.

[a] 1 = Male, 2 = Female.

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.005$, **** $p < 0.001$

Table 8.15

Correlations between the mild group children's beliefs about their asthma, demographic factors, illness characteristics and their self-reported psychological well-being

	SDQ scale						
Beliefs about asthma	TDS	IS	CP	H	ES	PP	PSB
Illness Identity	.44***	.11	.27	.10	.46***	.49***	-.08
Time-Line	.13	-.10	.25	.36*	-.15	-.15	-.21
Consequences	.48***	.30	.24	.16	.45***	.58****	-.04
Control - Medication	.13	.02	-.01	-.00	.38*	-.08	.12
Cause - Stress	.23	.45***	.08	.17	.15	.27	-.06
Exacerbation - Pollution	-.15	-.46***	-.22	-.18	.07	-.12	.24

	SDQ scale						
Demographic factor	TDS	IS	CP	H	ES	PP	PSB
Age of parent	-.20	-.27	-.36*	-.05	-.02	-.24	.05
Age of child	.04	-.01	.01	.00	.04	.05	-.25
Sex of child[a]	-.15	-.21	-.34*	-.21	.04	.09	.42**
Single parent household	.05	-.03	-.05	.04	.03	.13	-.06
Number of children	.14	.14	.31	.14	.00	-.06	-.28
Number of smokers	.27	.38*	.19	.30	.01	.28	-.28
Underprivileged area score	.24	.10	.16	.19	.01	.38*	.05

	SDQ scale						
Illness characteristic	TDS	IS	CP	H	ES	PP	PSB
Age at diagnosis[b]	-.10	.09	-.29	.04	-.00	-.14	.14
Duration of diagnosis[b]	.11	-.09	.29	-.05	.02	.16	-.21
Duration of pre-diagnosis awareness[c]	-.06	-.11	-.07	.14	-.07	-.25	-.13
Time since last attack[d]	-.23	-.24	-.03	-.26	-.13	-.13	.21

Note. TDS Total Difficulties; IS Impact; CP Conduct Problems; H Hyperactivity; ES Emotional Symptoms; PP Peer Problems; PSB Pro-social Behaviour.

Note. n = 40.

[a] 1 = Male, 2 = Female. [b] n = 39. [c] n = 37. [d] n = 30.

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.005$, **** $p < 0.001$

Table 8.16

Correlations between the severe group children's beliefs about their asthma, demographic factors, illness characteristics and their self-reported psychological well-being

	SDQ scale						
Beliefs about asthma	TDS	IS	CP	H	ES	PP	PSB
Illness Identity	.44	.26	.46	.34	.21	.22	-.22
Time-Line	-.22	.19	.00	-.39	-.16	-.04	-.24
Consequences	.08	.07	.34	.12	.07	-.24	-.87****
Control - Medication	.37	-.31	.13	-.10	.64*	.44	.12
Cause - Diet	-.57*	-.38	-.54	-.69**	.07	-.36	-.38
Cause - My fault	-.48	-.77***	-.59*	-.63*	.29	-.32	-.25
Cause - No-one's fault	-.77***	-.57*	-.50	-.50	-.34	-.78***	-.41

	SDQ scale						
Demographic factor	TDS	IS	CP	H	ES	PP	PSB
Age of parent	-.57*	-.30	-.73**	-.40	-.16	-.33	.35
Age of child	.19	-.12	.01	-.06	.35	.26	.11
Sex of child[a]	-.24	-.12	-.31	-.47	.10	.04	.09
Single parent household	-.16	-.08	-.20	-.14	-.08	-.04	.31
Number of children	-.09	-.01	.25	.13	-.26	-.36	-.24
Number of smokers	.73**	.13	.50	.42	.45	.67*	.19
Underprivileged area score	.44	.14	.43	.36	.32	.15	-.10

	SDQ scale						
Illness characteristic	TDS	IS	CP	H	ES	PP	PSB
Age at diagnosis	.42	.40	.24	.12	.44	.41	.07
Duration of diagnosis	-.38	-.45	-.25	-.14	-.35	-.35	-.04
Duration of pre-diagnosis awareness	-.30	-.38	-.10	-.08	-.21	-.45	-.40
Time since last attack[b]	-.43	-.48	-.10	-.11	-.43	-.58	-.41

Note. TDS Total Difficulties; IS Impact; CP Conduct Problems; H Hyperactivity; ES Emotional Symptoms; PP Peer Problems; PSB Pro-social Behaviour.

Note. n = 13.

[a] 1 = Male, 2 = Female. [b] n = 11.

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.005$, **** $p < 0.001$

beliefs about asthma, demographic and illness variables were less strongly associated with the SDQ (S11-16) outcome measures.

Although the number of smokers in the household was significantly associated with the child's parent- and self-reported peer problems (Table 8.11 and Table 8.14), after controlling for underprivileged area scores, these associations were no longer significant. In contrast, controlling for underprivileged area scores revealed an increase in the strength of association between the number of smokers in the household and the children's parent-reported Impact Score (all parents; $r = 0.40$; $n = 53$, $p < 0.005$; mild group parents; $r = 0.51$; $n = 28$, $p < 0.005$) and the severe group children's self-reported Total Difficulties ($r = 0.81$; $n = 13$, $p < 0.005$).

8.3.3 Data Analysis 3

Reasons for Achieving Good Control of Asthma

The coding framework that was derived from the responses of the sample in study 3 was used to code the participants' reasons for achieving good control of asthma.[2] Two independent raters coded a random selection of 161 responses that constituted approximately 10% of all responses. Cohen's kappa coefficient was 0.63.

[2] To simplify the application of the coding framework and avoid tautologies (Bagozzi & Dabholkar, 1994), within a set of linked responses, each domain was allocated a code only on the first occasion of its representation.

For each participant, a note was made of the domains that were represented in their reasoning and of the linkages that occurred between the domains. Data concerning the representation of each domain are presented in Table 8.17 and Table 8.18. The mean number of reasons for achieving good control of asthma, and the mean number of linkages did not differ significantly as a function of severity group (Table 8.19).

Physical, Affect, Psychological, Quality of Life, Interpersonal and Recreation domains characterised the reasoning of the parents (Table 8.20). Although the proportion of reasons did not differ as a function of severity group, there was a trend towards a higher proportion of Family and Education reasons amongst the mild and severe group parents respectively. The reasoning of the parents was least often characterised by the Medical and the Health Service domains.

Physical, Interpersonal, Affect, Recreation and Quality of Life domains also characterised the reasoning of the children (Table 8.21). Although the proportion of reasons did not differ significantly as a function of severity group, there was a trend towards a higher proportion of Medication, Education and Quality of Life reasons amongst the severe group children, and a higher proportion of Psychological and Interpersonal reasons amongst the mild group children. The reasoning of the children was least often characterised by the Health Service and the Family domains.

Tables 8.22-8.25 represent the implication matrices that were derived from the parents' and the children's reports.

Table 8.17

Implication Matrix Derived from Parents' Reasons for Achieving Good Control of their Child's Asthma

Abstract Ratio		Reason	1	2	3	4	5	6	7	8	9	10	11	*Out degrees*
0.12	1	Medication		0	0	7	0	4	0	7	0	3	1	22
0.14	2	Medical	0		2	1	0	1	0	2	4	0	2	12
0.23	3	Recreation	0	0		8	0	12	1	22	1	17	17	78
0.26	4	Physical	2	2	6		3	23	4	25	1	11	18	95
0.43	5	Education	0	0	0	0		6	0	2	0	3	2	13
0.47	6	Quality of Life	0	0	4	3	1		2	28	1	18	38	95
0.52	7	Family	0	0	1	0	0	0		4	2	3	5	15
0.54	8	Affect	1	0	6	12	1	18	8		3	17	32	98
0.62	9	Other	0	0	0	1	0	1	0	3		1	2	8
0.69	10	Social	0	0	3	0	2	1	0	10	0		24	40
0.73	11	Psychological	0	0	1	2	3	18	1	11	1	16		53
		In degrees	3	2	23	34	10	84	16	114	13	89	141	529
		Mentions per goal	22	9	67	91	20	130	22	161	18	96	154	
		Number people mentioning goal ≥ 1	20	9	42	49	18	49	16	52	16	43	49	
		Percent	38	17	79	93	34	93	30	98	30	81	93	

Note. n = 53.

Note. 'Aspects of the Health Service' was excluded from the implication matrix because it was referred to only once in a link with 'Other', and once in a link with 'Medical'.

Table 8.18

Implication Matrix Derived from Children's Reasons for Achieving Good Control of their Asthma

Abstract Ratio		Reason	1	2	3	4	5	6	7	8	9	10	11	*Out degrees*
0.14	1	Medication		2	5	3	1	5	7	1	2	9	2	37
0.20	2	Physical	4		14	10	3	9	17	10	0	21	6	94
0.25	3	Recreation	0	8		0	5	12	32	4	0	55	15	131
0.36	4	Medical	0	1	8		1	1	2	5	3	7	0	28
0.49	5	Other	1	2	1	3		4	1	0	0	6	2	20
0.60	6	Quality of Life	1	1	5	0	1		11	0	0	14	6	39
0.62	7	Social	0	1	3	0	2	4		2	0	29	12	53
0.64	8	Education	0	0	0	0	0	10	1		0	3	3	17
0.67	9	Family	0	0	0	0	0	0	0	0		3	0	3
0.71	10	Affect	0	7	6	0	6	11	12	5	1		13	61
0.78	11	Psychological	0	1	2	0	0	3	2	3	0	6		17
		In degrees	6	23	44	16	19	59	85	30	6	153	59	500
		Mentions per goal	33	100	130	27	27	73	102	29	7	172	65	
		Number people mentioning goal ≥ 1	23	43	51	17	22	41	42	24	5	49	29	
		Percent	44	83	98	33	42	79	81	46	10	94	56	

Note. n = 53.

Note. 'Aspects of the Health Service' was excluded from the implication matrix because it was referred to only once in a link with 'Other', and once in a link with 'Medical'.

Table 8.19

Number of Reasons for Achieving Good Control of Asthma and Links Between Reasons by Respondent Group and Asthma Severity

	Parents					
	Mean number		Standard deviation		Sample size	
Variable	Mild	Severe	Mild	Severe	Mild	Severe
Reasons	15.4	13.5	3.7	2.6	40	13
Links	10.5	8.7	3.6	3.0	40	13

	Children					
	Mean number		Standard deviation		Sample size	
Variable	Mild	Severe	Mild	Severe	Mild	Severe
Reasons	14.8	14.5	5.1	3.8	39	13
Links	9.7	9.5	4.6	3.0	39	13

Table 8.20

Parents' Reasons for Achieving Good Control of their Child's Asthma by Asthma Severity

	Severity	
Reason	Mild[a]	Severe[b]
Physical	36 (90.0)	13 (100.0)
Medical	7 (17.5)	2 (15.4)
Health Service	1 (2.5)	0 (0.0)
Medication	14 (35.0)	6 (46.2)
Social	33 (82.5)	10 (76.9)
Affect	40 (100.0)	12 (92.3)
Psychological	37 (92.5)	12 (92.3)
Recreation	31 (77.5)	11 (84.6)
Education	11 (27.5)	7 (53.8)
Quality of life	36 (90.0)	13 (100.0)
Family	15 (37.5)	1 (7.7)
Other	12 (30.0)	4 (30.8)

Note. Percentages are presented in parentheses.

[a] n = 40. [b] n = 13.

Table 8.21

Children's Reasons for Achieving Good Control of their Asthma by Asthma Severity

	Severity	
Reason	Mild[a]	Severe[b]
Physical	32 (82.1)	11 (84.6)
Medical	12 (30.8)	5 (38.5)
Health Service	1 (2.6)	0 (0.0)
Medication	15 (38.5)	8 (61.5)
Social	33 (84.6)	9 (69.2)
Affect	37 (94.9)	12 (92.3)
Psychological	25 (64.1)	4 (30.8)
Recreation	38 (97.4)	13 (100.0)
Education	15 (38.5)	9 (69.2)
Quality of life	29 (74.4)	12 (92.3)
Family	3 (7.7)	2 (15.4)
Other	19 (47.5)	3 (23.1)

Note. Percentages are presented in parentheses.

[a] n = 39. [b] n = 13.

Table 8.22

Implication Matrix Derived from Mild Group Parents' Reasons for Achieving Good Control of their Child's Asthma

Abstract Ratio		Reason	1	2	3	4	5	6	7	8	9	10	11	*Out degrees*
0.10	1	Medical		0	0	2	1	0	2	0	3	0	1	9
0.15	2	Medication	0		4	0	4	0	5	0	0	3	1	17
0.23	3	Physical	1	2		5	18	3	19	2	0	9	16	75
0.27	4	Recreation	0	0	5		9	1	14	0	1	13	14	57
0.49	5	Quality of Life	0	0	3	3		2	18	1	1	12	31	71
0.50	6	Family	0	0	0	1	0		4	0	2	3	5	15
0.51	7	Affect	0	1	9	6	13	8		1	2	13	29	82
0.53	8	Education	0	0	0	0	4	0	1		0	1	1	7
0.59	9	Other	0	0	1	0	1	0	3	0		1	1	7
0.66	10	Social	0	0	0	3	0	0	10	2	0		19	34
0.74	11	Psychological	0	0	1	1	17	1	8	2	1	11		42
		In degrees	1	3	23	21	67	15	84	8	10	66	118	416
		Mentions per goal	7	16	66	51	101	21	127	13	14	73	125	
		Number people mentioning goal ≥ 1	7	14	36	31	36	15	40	11	12	33	37	
		Percent	18	35	90	78	90	38	100	28	30	83	93	

Note. n = 40.

Note. 'Aspects of the Health Service' was excluded from the implication matrix because it was referred to only once in a link with 'Other', and once in a link with 'Medical'.

Table 8.23

Implication Matrix Derived from Severe Group Parents' Reasons for Achieving Good Control of their Child's Asthma

Abstract Ratio		Reason	1	2	3	4	5	6	7	8	9	10	11	*Out degrees*
0.00	1	Medication		0	0	0	3	0	2	0	0	0	0	5
0.09	2	Recreation	0		0	0	3	3	8	3	0	4	0	21
0.25	3	Education	0	0		0	0	2	1	1	0	2	0	6
0.25	4	Medical	0	0	0		1	0	0	1	1	0	0	3
0.35	5	Physical	0	1	1	1		5	6	2	1	2	1	20
0.41	6	Quality of Life	0	1	0	0	0		10	7	0	6	0	24
0.65	7	Affect	0	0	0	0	3	5		3	1	4	0	16
0.68	8	Psychological	0	0	1	0	1	1	3		0	5	0	11
0.75	9	Other	0	0	0	0	0	0	0	1		0	0	1
0.79	10	Social	0	0	0	0	0	1	0	5	0		0	6
1.00	11	Family	0	0	0	0	0	0	0	0	0	0		0
		In degrees	0	2	2	1	11	17	30	23	3	23	1	113
		Mentions per goal	6	16	7	2	25	29	34	29	4	23	1	
		Number people mentioning goal ≥ 1	6	11	7	2	13	13	12	12	4	10	1	
		Percent	46	85	54	15	100	100	92	92	31	77	8	

Note. n = 13.

Note. 'Aspects of the Health Service' was excluded from the implication matrix because it was referred to only once in a link with 'Other', and once in a link with 'Medical'.

Table 8.24

Implication Matrix Derived from Mild Group Children's Reasons for Achieving Good Control of their Asthma

Abstract Ratio		Reason	1	2	3	4	5	6	7	8	9	10	11	*Out degrees*
0.18	1	Medication		2	0	2	1	5	3	0	7	1	2	23
0.22	2	Physical	3		9	7	3	14	7	9	14	0	6	72
0.23	3	Recreation	0	6		0	4	23	7	4	39	0	11	94
0.35	4	Medical	0	1	7		1	2	0	2	6	3	0	22
0.47	5	Other	1	2	1	3		1	3	0	6	0	2	19
0.59	6	Social	0	1	2	0	1		3	2	24	0	12	45
0.60	7	Quality of Life	1	0	3	0	1	7		0	9	0	4	25
0.65	8	Education	0	0	0	0	0	0	7		2	0	3	12
0.70	9	Affect	0	7	4	0	6	10	5	3		1	12	48
0.71	10	Family	0	0	0	0	0	0	0	0	2		0	2
0.78	11	Psychological	0	1	2	0	0	2	3	2	5	0		15
		In degrees	5	20	28	12	17	64	38	22	114	5	52	377
		Mentions per goal	33	100	130	27	27	73	102	29	7	172	65	
		Number people mentioning goal ≥ 1	23	43	51	17	22	41	42	24	5	49	29	
		Percent	44	83	98	33	42	79	81	46	10	94	56	

Note. n = 39.

Note. 'Aspects of the Health Service' was excluded from the implication matrix because it was referred to only once in a link with 'Other', and once in a link with 'Medical'.

Table 8.25

Implication Matrix Derived from Severe Group Children's Reasons for Achieving Good Control of their Asthma

Abstract Ratio		Reason	1	2	3	4	5	6	7	8	9	10	11	*Out degrees*
0.07	1	Medication		0	5	1	1	2	1	0	2	2	0	14
0.12	2	Physical	1		5	3	0	2	1	0	3	7	0	22
0.30	3	Recreation	0	2		0	0	5	0	1	9	16	4	37
0.40	4	Medical	0	0	1		0	1	3	0	0	1	0	6
0.50	5	Family	0	0	0	0		0	0	0	0	1	0	1
0.60	6	Quality of Life	0	1	2	0	0		0	0	4	5	2	14
0.62	7	Education	0	0	0	0	0	3		0	1	1	0	5
0.67	8	Other	0	0	0	0	0	1	0		0	0	0	1
0.72	9	Social	0	0	1	0	0	1	0	1		5	0	8
0.75	10	Affect	0	0	2	0	0	6	2	0	2		1	13
0.78	11	Psychological	0	0	0	0	0	0	1	0	0	1		2
		In degrees	1	3	16	4	1	21	8	2	21	39	7	123
		Mentions per goal	11	21	40	8	2	26	9	3	19	42	8	
		Number people mentioning goal ≥ 1	8	11	13	5	2	12	9	3	9	12	4	
		Percent	62	85	100	39	15	92	69	23	69	92	31	

Note. n = 13.

Note. 'Aspects of the Health Service' was excluded from the implication matrix because it was referred to only once in a link with 'Other', and once in a link with 'Medical'.

Social and psychological reasons for achieving good control of asthma, the most abstract of the parents' reasons, featured at a similar level of abstraction in the reasoning of the mild and the severe group parents. The Family and Affect domains were also abstract in the motivation system of the severe group parents (Table 8.26). Quality of Life, Psychological and Affect domains were central amongst the network of reasons for the mild and the severe group parents. Although Affect and Psychological domains were prestigious for both the mild and the severe group parents, generally, the target of their reasons was psychological well-being and emotional well-being respectively.

The children's most abstract reasons for achieving good control of asthma were representative of the Education, Interpersonal, Family, Psychological, Affect and Quality of Life domains. Although the reasons of the mild and severe group children were generally reported at a similar level of abstraction, in comparison with the mild group, the Social domain was more abstract for the severe group (Table 8.27). Affect and Recreation domains were central amongst the children's network of reasons. However, in comparison with the motivation system of the mild group, the Recreation domain assumed greater centrality in that of the severe group. Affect was most often the target of reasons for achieving good control of asthma in the networks of the children. Medical, Medication and Family domains were the least central of the domains in the network of the children, and in comparison with that of the mild group, the Psychological domain was less central in the network of the severe group.

Table 8.26

Parents' Reasons for Achieving Good Control of their Child's Asthma by Asthma Severity: Abstractness, Centrality and Prestige

	Mild[a]			Severe[b]		
Reason	Abstractness	Centrality	Prestige	Abstractness	Centrality	Prestige
Medical	.10	.02	.00	.25	.04	.01
Medication	.15	.05	.01	.00	.04	.00
Physical	.23	.24	.06	.35	.27	.10
Recreation	.27	.19	.05	.09	.20	.02
Quality of Life	.49	.33	.16	.41	.36	.15
Family	.50	.07	.04	1.00	.01	.01
Affect	.51	.40	.20	.65	.41	.27
Education	.53	.04	.02	.25	.07	.02
Other	.59	.04	.02	.75	.04	.03
Social	.66	.24	.16	.79	.08	.20
Psychological	.74	.38	.28	.68	.30	.20

[a] n = 40. [b] n = 13.

Table 8.27

Children's Reasons for Achieving Good Control of their Asthma by Asthma Severity: Abstractness, Centrality and Prestige

Reason	Mild[a]			Severe[b]		
	Abstractness	Centrality	Prestige	Abstractness	Centrality	Prestige
Medication	.18	.07	.01	.07	.12	.01
Physical	.22	.24	.05	.12	.20	.02
Recreation	.23	.32	.07	.30	.43	.13
Medical	.35	.09	.03	.40	.08	.03
Other	.47	.10	.05	.67	.02	.02
Social	.59	.29	.17	.72	.24	.17
Quality of Life	.60	.17	.10	.60	.28	.17
Education	.65	.10	.06	.62	.11	.07
Affect	.70	.43	.30	.75	.42	.32
Family	.71	.02	.01	.50	.02	.01
Psychological	.78	.18	.14	.78	.07	.06

[a] n = 39. [b] n = 13.

8.3.4 Data Analysis 4

Children's Description of What Out of Breath Feels Like

Descriptions of breathlessness were coded for the occurrence of any of the eight response categories derived from study 1 (Table 5.4).[3] Examination of the data suggested additional categories, and content analysis generated a further five response categories: (i) "Chest Tightness", (ii) "Negative Affect", (iii) "Inability", (iv) "Airflow", and (v) "Weakness". Definitions are presented in Table 8.28.

Out of breath was often described in terms of how someone might breathe when they were out of breath (42.0% of sample), as difficulty in breathing (38.0% of sample) and as chest tightness (42% of the sample). An equivalent proportion of the sample (16-18%) referred to cough, an inability to do anything, tiredness, weakness, wheeze, negative affect, and restricted airflow. Twenty-one children (42.0%) provided more detailed descriptions of what out of breath feels like.

These detailed descriptions were similar to those reported in the previous studies insofar as they often referred to an internal, subjective sensation. For example, "Feels like you can't feel the back of your mouth, like it's not there" (11-year-old girl at Step 1); "Feels like there's something inside you that's pulling something, making you short of breath" (12-year-old girl at Step 1). Some descriptions introduced an 'other', for example, "Feels like being choked" (10-year-old girl at Step 2); "Like someone's got their hand round your chest and is squeezing it" (10-year-old girl at Step 2); "Like windpipe's being squeezed" (12-year-old girl at Step 2).

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[3] The definition of the response category "Sore Throat" was expanded to include reference to tightness or other sensations in the throat.

Table 8.28

Descriptions of Breathlessness: Supplementary Categories

Description category	Definition
Chest tightness	Reference to chest tightness
Negative affect	Reference to negative affect
Inability	Reference to an inability to do something. For example, just can't do anything
Airflow	Reference to airflow. For example, can't bring air in
Weakness	Reference to weakness

In the detailed reports, when the children referred to tightness and wheeze, these sensations of respiratory distress were often internalised. For example, "Feels wheezy inside my chest" (11-year-old girl at Step 2); "Kind of tight in the back of your throat, tight in lungs" (11-year-old boy at Step 2); "My throat clenches up a bit. My lungs feel really tight" (12-year-old boy at Step 2); "My oesophagus is tight" (12-year-old boy at Step 3); "Feels like it's tiny, that hole thing" [pointing at throat] (12-year-old girl at Step 4). Throat or chest tightness was sometimes linked with restricted airflow. For example, "Like got blockage in throat, feeling that is. Can't bring in air 'cos lungs too tight to be able to take in big breaths of air" (11-year-old boy at Step 3); "Get a tight, feels like getting a tight throat and is stopping you getting air in. It sometimes hurts your ribs. Feels like your ribs are being pushed together. Can get pains in the bottom of your chest" (11-year-old boy at Step 4).

The most detailed description of what out of breath feels like incorporated a variety of behavioural, physiological, interpersonal, social and psychological features: "Feel like I can't go any faster or further, struggling to get air, chest goes tight, but I'm not quite wheezing. My, all my friends are either fine or okay. I'm there huffing and puffing. They're all ahead of me in the race and I can't finish. When my chest tightens up, all my friends are laughing at me. I'm wheezing, huffing and puffing or coughing. Bullies like picking on people 'cos they're wheezing or out of breath and they've finished, coming last in races, being blamed for not trying, being looked down on, being criticised, like spiralling downwards and you can't get back up. Like you're falling or climbing and you can't reach the top. Trying to encourage you but you feel like you can't do it no matter how hard you try" (11-year-old girl at Step 2).

Descriptions of What Out of Breath Feels Like: Inter-Correlations

Chest tightness, as a descriptor of breathlessness, was significantly associated with the descriptor 'Wheeze' ($r = 0.45$; $n = 50$, $p < 0.005$), and reports of airflow restriction (when asked what out of breath feels like) were significantly associated with 'Negative Affect' ($r = 0.36$; $n = 50$, $p < 0.01$).

Descriptions of What Out of Breath Feels Like: Associations with Disease Severity and Belief Concordance

Descriptions of what out of breath feels like were not correlated with disease severity, or concordance in the beliefs of the parents and their child concerning the child's asthma, or concordance in the beliefs of the parents and their child concerning the signs and symptoms of the child's asthma.

8.4 Discussion

8.4.1 Data Analysis 1

The analysis has shown that beliefs of the parents and the children about the child's asthma were relatively independent of asthma severity. In comparison with the parents of the children with severe asthma, the parents of the children with mild asthma did not have a weaker Identity belief and did not differ significantly in their beliefs about the seriousness of their child's asthma or its controllability. Similarly, the children's strength of Identity belief did not differ significantly as a function of severity group. In comparison with the children with severe asthma, although the children with mild asthma perceived asthma generally to be less serious, they did not differ significantly in their perception of the seriousness of their asthma. Although the majority of the children believed that their medication was effective in controlling their symptoms, and this is consistent with the findings of study 3, contrary to prediction, in comparison with the mild group, the children with severe asthma were more likely to agree that there was a lot that they could do to control their symptoms.

The low number of children with severe asthma was a limitation of the present study. Although the differences between the IPQ 'Identity' and 'Consequences' scores of the mild and the severe group were generally in the expected direction, the small sample size made it unlikely that any small but genuine effects would be detected. The method of scoring the IPQ Identity scale may also have obscured any differences between the severity groups as the scale total is derived from the number of symptoms reported rather than the frequency or intensity of symptoms.

The perceived seriousness of asthma is likely to vary according to the impact that a child's condition has on their and their family's routine. Consistent with the hypothesis that mild asthma would be associated with a perception of less serious consequences, in comparison with the children in the severe group, the children with mild asthma perceived asthma generally to have less serious consequences. However, the parents' and the children's perception of the seriousness of the child's asthma did not differ significantly as a function of severity group. Either the consequences of mild and severe asthma constituted an equivalent degree of perceived disruption, and this is possible given the suggestion that individuals may differ in their interpretation of serious consequences (see study 3, data analysis 1), or a child's step of treatment and/or the participants' asthma management behaviour were effective in mitigating the consequences of the child's condition.

Although it was hypothesised that mild asthma would be associated with the participants' perception that asthma was controllable, Cure/Control beliefs were generally independent of disease severity. Contrary to prediction, in comparison with the children in the mild group, the children with severe asthma were more likely to agree that there was a lot that they could do to control their symptoms. In comparison with the children in the mild group, these children may have assumed greater responsibility for the management of their condition and/or experienced a wider variety of asthma management behaviours.

In conclusion, the analysis has shown that the beliefs of the parents and the children about the child's asthma were generally independent of the severity of the child's condition. However, the IPQ Identity scale scoring system and the small sample size may have limited the sensitivity and the power of the study respectively. In comparison with the objective severity of a patient's disease, the patient's perception of its consequences may be a better predictor of their beliefs about its seriousness. Severe asthma was suggested to be associated with a child's awareness of various asthma management strategies that may relieve and prevent their symptoms.

8.4.2 Data Analysis 2

The analysis has shown that, although a proportion of children with asthma experienced psychological difficulties, and severe asthma may be associated with a child's self-report of hyperactivity, as a group, the children tended to function within the normal range on the SDQ measure of psychological functioning. This is consistent with previous studies (Kashani et al., 1988; Nassau & Drotar, 1995; Wamboldt et al., 1998). The parents' perception of the extent to which their child's asthma was controlled was associated with the psychological well-being of the children with mild asthma but was unrelated to the psychological well-being of the children with severe asthma. Although the children's psychological difficulties were associated with beliefs about the child's asthma, parent factors were also associated with reports of the child's difficulties. Shared beliefs about the child's asthma and its consequences were associated with a lower incidence of the children's parent-reported difficulties.

Although the literature suggested that more severe asthma might be associated with a greater degree of psychological disturbance (e.g., Graham et al., 1967; McNichol et al., 1973; Peckham & Butler, 1978; Wamboldt et al., 1998), the results generally did not support this hypothesis, and suggested that factors other than illness severity may determine the psychological well-being of children with asthma. This is consistent with other studies (Kashani et al., 1988; Nassau & Drotar. 1995; Norrish et al., 1977). However, with the exception of the children's self-reported emotional difficulties, which were identified at a similar rate in a sample of children with asthma (Meltzer, Gatward, Goodman & Ford, 2000), in comparison with Meltzer et al.'s (2000) survey results, there were higher rates of psychological disturbance in the study sample.

Also, the findings of the present study suggested that children with severe asthma might be at risk of suffering from restlessness, fidgeting, concentration difficulties, impulsivity and problems with task completion. Although Roth, Beyreiss, Schlenzka and Beyer (1991) suggested a relationship between atopic eczema and attention problems and restlessness, Biederman, Milberger, Faraone, Guite and Warburton (1994) concluded that there was no evidence to suggest an aetiological or pathophysiological relationship between ADHD and asthma. McGee, Stanton and Sears (1993) reported no association between allergic disorders and reports of attention deficit and hyperactivity. However, rarely, in children with asthma, use of β_2-agonist reliever medication may be associated with hyperactivity (Association of the British Pharmaceutical Industry, 1996). Patients who are anxious about their asthma or who have reservations about the use of preventative mediation may over-use their reliever medication (Dirks et al., 1977; Dirks et al., 1978; Osman et al., 1993).

Perceived control of asthma, the parent-rated item included in the demographic and clinical information questionnaire, was associated with the psychological well-being of the children with mild asthma and this is consistent with Norrish et al.'s (1977) report of an association between disease control and psychological adjustment. However, in the present study, the same item was not associated with the psychological well-being of the children with severe asthma and was of less predictive utility when other parent factors were considered. When asthma management requires high levels of medication to control the child's symptoms, in comparison with perceptions of disease control, concerns and beliefs about the child's medication may be of greater salience to the respondents. Perceptions of disease control may be of limited utility in screening for children who are at risk of suffering from psychological disturbance, although children's perceptions of disease control may be associated with their self-reported psychological well-being.

In the present study, perceptions of the seriousness of the child's asthma were associated with reports of the child's psychological difficulties. This is consistent with the findings of study 3 (data analysis 2). Less serious asthma, or less serious consequences, real or perceived, might lead to less disruption to normal routines and activities which, consequently, is likely to be associated with less disease-related conflict and stress. It was noteworthy that, although the parents' perception of the consequences of their child's severe asthma was associated with their rating of their child's psychological difficulties, the parents' perception of the consequences of their child's mild asthma was unrelated to their reports of their child's psychological well-being. In contrast, whether mild or severe, the children's perception of the consequences of their asthma was significantly associated with their self-reported psychological well-being. Parents may perceive their child's asthma to be a stressor only insofar as it impacts upon the functioning of the family. In this respect, mild asthma may be a weak stressor that has few implications for the parents' reports of their child's psychological well-being. In contrast, children may perceive their asthma to be a stressor when it has an impact on any aspect of their life, for example, having to take regular medication or rest during sports.

In the severe group, the children's expression of strong agreement/disagreement with IPQ Cause items was associated with their self-reported psychological difficulties. A tendency toward strong agreement/disagreement may indicate a predisposition toward "all-or-nothing" thinking, a form of reasoning that has been associated with psychological difficulties (Fennell, 1989).

In the present study, the number of household smokers was associated with the children's psychological well-being. Although partial correlations to control for social deprivation suggested that smoking status was no longer associated with the children's parent- and self-reported peer problems, the associations with the children's parent-reported impact of any psychological difficulties of their child, and the children's self-reported psychological well-being remained significant. It is noteworthy that many parents who lived in smoking households emphasised that smoking occurred either outside or in a room away from their child. Rarely, a child living in these households reported feeling guilty because their parent had to go outside to smoke, or feeling upset because they could not be in the same room as their parent when their parent was smoking.

Whereas the parents' perceptions of the consequences of their child's severe asthma were predictive of their reports of the child's psychological difficulties, the extent to which the parents and the child shared beliefs concerning the seriousness of the child's asthma was significantly negatively associated with the child's parent-reported conduct problems. This is consistent with the findings of study 3 (data analysis 2) and suggests that a family's quality of life, and a child's perceptions of family support and understanding, may mediate the relationship between illness beliefs and the child's psychological well-being.

In conclusion, it is suggested that, beliefs about a child's asthma may be particularly useful in predicting the child's psychological well-being. Possible moderating effects of parent factors and beliefs about asthma may explain the inconsistencies in the literature. Belief concordance may be associated with less conflict within the family concerning the child's disease and with the child's perception of family support and understanding. In this respect, belief concordance may be a distal determinant of children's psychological well-being that operates through its impact on family interaction and the child's perceptions.

8.4.3 Data Analysis 3

Reasons for achieving good control of asthma did not differ significantly in content, or the proportion of respondents who expressed reasons that were representative of a domain, as a function of severity group. The parents' motivation system was characterised by abstract Social and Psychological reasons, organised around the central domains of Affect, Psychology and Quality of Life. Generally, the target of the mild and severe group parents' reasons was psychological and emotional well-being respectively. The children's motivation system was characterised by abstract Education, Family, Interpersonal, Psychological, Affect and Quality of Life reasons, organised around the central domains of Recreation and Affect. In comparison with the motivation system of the mild group, Recreation and Psychology assumed greater and less centrality respectively in the motivation system of the severe group children. Affect was the main target of the children's reasons for achieving good control of asthma.

Although it was hypothesised that, because of the potential impact of severe asthma, in comparison with mild asthma, severe asthma would be associated with more reasons for achieving good control of asthma, the findings of the present analysis did not support this hypothesis. It is suggested that the nature of the task i.e., explicitly asking the participants to think of five reasons for achieving good control of asthma, effectively minimised any between severity group differences in the number of reasons elicited, and revealed how the experience of asthma and reasons for achieving good control of asthma varied as a function of severity group.

The analysis has shown that, from the perspective of the mild group participants, concerns about physical symptoms, restriction of or interference with activities, use of medication (and unpleasant aspects of treatment) and the burden of seeking medical assistance represented concrete reasons for achieving good control of asthma. The severe group parents, who also talked about less time off school as a reason for achieving good control of asthma, expressed similar concerns. From the perspective of a child with severe asthma, the physical symptoms of asthma, the unpleasant aspects of its treatment e.g., the taste of inhalers, and restriction of or interference with activities were concrete reasons for achieving good control of their condition. These findings are consistent with those of other studies (Action Asthma, 1993; Donnelly et al., 1987; French & Chrisitie, 1996; Hilton, 1991; Paterson & Britten, 2000; Pradel et al., 2001).

At a more abstract level, the mild group parents believed that achieving good control of asthma was important because it presented less disruption to their child's social activities and interpersonal relationships, and was associated with positive psychological outcomes, including self-confidence and self-esteem. The severe group parents believed that achieving good control of asthma was important for the same reasons, and because it was associated with positive affect and less disruption to family activities. The children, in addition, were motivated at an abstract level by education and general quality of life i.e., less disruption to normal daily routines, and opportunities in the future. The participants' representation of low abstract level (physical) and high abstract level (quality of life, emotional regulation and affect, psychological) reasons for achieving good control of asthma is consistent with Leventhal et al.'s (1984) model of a parallel system of physical and emotional regulation.

Insofar as medication requirements (step of treatment) represent disease severity, a higher step of treatment may indicate asthma that was more difficult to control. Children in the severe group, before their asthma was brought under control, may have experienced a considerable number of illness episodes. Acute exacerbation of asthma has been linked with the experience of worry and fright (Kinsman et al., 1977; Kinsman et al., 1973). Some patients have reported anxiety about asthma getting worse with age (Osman et al., 1993). Other emotional consequences that may be particularly salient for the children with severe asthma include worry about possible future attacks and their ability to deal with them, and embarrassment about the use of inhalers in public (French & Christie, 1996; Gibson et al., 1995; Nocon & Booth, 1991). Parents of children with asthma may share these concerns and worry about the long-term impact of asthma in terms of lifestyle and well-being (Nocon & Booth, 1991; Paterson & Britten, 2000). This context may explain why emotional well-being was prestigious in the severe group parents' motivation system. The finding that psychological functioning and psychological well-being were prestigious reasons to achieve good control of asthma for the mild group parents may reflect a more general parental concern about their child's psychological health and self-concept.

Emotional well-being also was a prestigious reason to achieve good control of asthma for the children, and with 'Recreation' formed the core of the children's motivation system. That severe asthma may be associated with disruption to physical and leisure activities (Action Asthma, 1993; French & Christie, 1996; Pradel et al., 2001) may explain why the Recreation domain assumed greater centrality in the motivation system of the severe group children.

In conclusion, it is suggested that when practitioners intervene to improve a patient's adherence with their treatment recommendations, an emphasis on the affective and recreational benefits of achieving good control of asthma is likely to have the greatest impact on children with severe asthma.

8.4.4 Data Analysis 4

The analysis has shown that qualitative variability in the descriptions of breathlessness provided by a group of children with asthma was not correlated with the severity of the child's condition. The analysis has also shown that concordance in the beliefs of the parents and their child concerning the child's asthma, a potential index of family discussion about asthma, and concordance between the beliefs of the parents and their child concerning the signs and symptoms of the child's asthma, a potential indicator of parental sensitivity to their child's internal states, were not correlated with the child's description of what out of breath feels like. In comparison with the findings of study 1 and study 2, when asked to describe what out of breath feels like, a greater proportion of children referred to specific respiratory sensations e.g., chest tightness and wheeze. This is consistent with the suggestion that experience of asthma facilitates an awareness and differentiation of respiratory sensations.

Step of treatment and concordance in the beliefs of the parents and their child may be poor indicators of disease severity and the extent of family discussion about asthma respectively. Insofar as medication requirements are concerned, the course of a child's asthma and the effectiveness of medication may vary (Mrazek, 1985). An objective measure of lung function, and in particular lung function variability, is likely to be a more reliable indicator of experience with asthma-related episodes. Although concordance between the beliefs of the parents and their child concerning the child's asthma may be associated with family discussion about asthma, the labels that are used to describe the child's internal states may be independent of that concordance. For example, respiratory symptoms may be labelled and discussed as either primary infant states, e.g., tiredness, or differentiated respiratory sensations e.g., breathlessness.

However, the IPQ Identity items provided a structured profile of the signs and symptoms that may characterise a child's experience of asthma and included differentiated respiratory sensations such as 'Wheeze' and 'Out of Breath'. The finding that Identity concordance, a potential indicator of parental sensitivity to their child's respiratory sensations, was not correlated with the quality of the children's descriptions of breathlessness may be explained by the lack of variability in Identity concordance within the sample concerning the occurrence of breathlessness, wheeze and chest tightness.

In the present study, in comparison with study 1 and study 2, the children's descriptions of breathlessness suggested a more differentiated system of respiratory sensations. Content analysis generated five new response categories. In addition, a greater proportion of children referred to specific respiratory sensations, although this finding may have been an artefact of the method in that the IPQ Identity items may have primed the children's responses. The differentiated respiratory descriptor 'Chest Tightness' was significantly associated with another differentiated respiratory descriptor, 'Wheeze', and reference to negative affect in the context of breathlessness was significantly associated with the differentiated respiratory descriptor, 'Restriction of Airflow'. Chest tightness, wheeze, breathlessness and cough are the main symptoms of asthma (Ayres, 1999). The significant association between the sophisticated representation of breathlessness that included a reference to restricted airflow, and reference to asthma-related negative affect is consistent with the hypothesis that negative affect and family discussion may mediate the relationship between the experience of asthma and the acquisition of a sophisticated vocabulary with which to describe respiratory sensations.

8.5 Summary

To test the reliability of previous findings and improve our understanding of how disease severity is associated with different aspects of childhood asthma, interviews were conducted with fifty-three 10-13-year-old children with asthma and their parents. Forty children were at Step 1 or Step 2 of treatment according to the British Guidelines on Asthma Management (1997) (mild group), and thirteen children were at Step 3 or above (severe group). The interview procedure involved open-ended questions about the child's asthma, modified versions of the asthma-specific Illness Perception Questionnaire (Weinman et al., 1996), the extended version of the Strengths and Difficulties Questionnaire (Goodman, 1997; 1999; Goodman et al., 1998), and a cognitive task to determine the participants' reasons for achieving good control of asthma.

Discourse about the child's asthma did not vary as a function of severity group. Although it was hypothesised that, in comparison with severe asthma, mild asthma would be associated with fewer symptoms, less serious consequences and a greater degree of controllability, the participants' beliefs about the child's asthma were generally independent of disease severity. However, disease severity was significantly associated with a child's agreement that there was a lot that they could do to control their symptoms. It was concluded that the scoring system of the IPQ Identity scale and the limited power of the study might have contributed to the null findings. Severe asthma was suggested to be associated with a variety of relief and preventative strategies other than the use of medication and/or a child's greater degree of responsibility with respect to their asthma self-management.

With the exception of an association between asthma severity and a child's parent-reported SDQ Impact score, and their self-reported hyperactivity, asthma severity was not correlated with SDQ outcome. When a child was at a high step of treatment, the parents' beliefs about asthma, and in particular the seriousness of its consequences, were significantly associated with their reports of the child's psychological well-being. When a child was at a low step of treatment, in comparison with the parents' beliefs about asthma, demographic factors were a more reliable predictor. The children's beliefs about their asthma were significantly associated with their self-reported psychological well-being, although the pattern of association varied according to severity group. Concordance in the beliefs of the parents and their child about the child's asthma was significantly associated with the child's good psychological adjustment. It was concluded that a family's quality of life and a child's perceptions of family support and understanding may mediate the relationship between illness beliefs and the child's psychological well-being.

Reasons for achieving good control of asthma were consistent with those reported in study 3. Although the nature and frequency of occurrence of the respondents' reasons for achieving good control of asthma did not differ significantly as a function of severity group, there were differences in the organisation of their motivation system. It was suggested that an emphasis of the relevant domains of asthma intrusiveness would be most likely to encourage the initiation and maintenance of effective asthma management behaviour.

Disease severity defined by medication requirements, and concordance in the beliefs of the parents and their child were not correlated with the children's descriptions of what out of breath feels like.

Chapter 9

General Discussion

During the course of the research reported above, a great deal of time was spent with participants, listening to them talk about their experiences and views concerning childhood asthma. This was undoubtedly a highlight of the research, and from the children and parents who took part, I have learned a great deal about living and coping with childhood asthma. Perhaps the most interesting finding was that concordance in the beliefs of parents and their child about the child's asthma, and in particular the perceived seriousness of its consequences, was associated with the child's parent- and self-reported psychological well-being. Future study could explore the determinants and contingencies of this association in greater detail.

Children's awareness of respiratory sensations, their descriptions of breathlessness and their knowledge about the respiratory system were the foci of study 1 and study 2. The finding that not every older child with asthma described out of breath in terms of an internal sensation located within the respiratory system led to the conclusion that age and experience of asthma could not account for the quality of children's descriptions. A review of the developmental literature suggested that family discussion about illness might serve as an explanation. The focus of the research then switched to cognitive representations of childhood asthma.

Study 3 was designed to answer several questions relevant to a health psychological perspective on childhood asthma. Generally the findings were consistent with the literature on illness cognition and psychological outcomes with respect to asthma. Adapting a cognitive task from the literature to explore participants' reasons for achieving good control of asthma became an interesting area of study. Inductive content analysis provided a particularly educational and fascinating insight into the organisation of the participants' motivational systems. This may be a fruitful area for future study with respect to cognitive-behavioural interventions and motivational interviewing in primary care settings.

From study 3 and study 4, I have learned about the potential difficulty in recruiting children with asthma and their parents to a psychology research study. However, I have subsequently learned that illumination is not necessarily dependent on sample size.

In this respect, the largely quantitative analyses offered little opportunity to explore the gems of information that were discovered during research interviews. For example, learning about pet ownership negotiations and the context of parental smoking. This information was often elicited by the open-ended questions of the semi-structured interview. Although content analysis using the pre-determined framework derived from the illness cognition literature allowed the aims of the analysis to be achieved, a true inductive content analysis may have shed light on so much more of interest and clinical relevance.

The studies have shown that a child's age was significantly associated with their attributions of breathlessness and their knowledge about the respiratory system. Experience of asthma was significantly associated with attributions of respiratory symptoms. Age and experience of asthma were significantly associated with the quality of a child's description of what out of breath feels like. Although a structured assessment of the children's cognitive representation of asthma suggested that the children had a relatively good understanding of the different components of illness representation, when asked to talk about their asthma, they tended to focus on those aspects of their condition that were salient to their normal, daily functioning i.e., symptoms, causes of exacerbation and consequences.

Although the beliefs of the parents and their child about asthma were reasonably concordant with respect to the 'Identity' of the child's asthma, there was less concordance with respect to the other components of illness representation.

Mean SDQ scores were all within the normal range. The nature and extent of the children's psychological difficulties varied according to the source of information about the child. The parents' reports tended to suggest that the children experienced a variety of difficulties including hyperactivity, emotional symptoms and peer problems. The children's self- reports indicated fewer cases, and suggested that any difficulties were likely to be conduct problems.

Aspects of the intrusiveness of asthma were similar for all the participants. The organisation of their network of reasons for achieving good control of asthma varied as a function of respondent and severity group.

Although the number of children at Step 3 and Step 4 who were successfully recruited to study 4 were consistent with sample characteristics reported elsewhere (e.g., Stevens, Wesseldine, Couriel, Dyer, Osman & Silverman, 2002), the low response rate in the studies that examined perceptions of asthma was the main limitation of the research programme. This was a particular concern as it reduced the power of the studies considerably and raised the possibility that the sample was not representative of the population of childhood asthma sufferers and their parents.[1] The difficulties that were experienced in patient recruitment occurred at two distinct levels: (i) recruitment of primary care practices to assist with patient recruitment, and (ii) recruitment of patients.

Although it has been reported that the majority of a sample of general practitioners considered research to be important, less than one seventh were involved in on-going research (Robinson & Gould, 2000). The main area of the doctors' personal interest was chronic illness, and in particular respiratory conditions. However, in comparison with cardiovascular disease, mental health and patient education, asthma and other respiratory conditions were considered less of a priority. This finding may explain the significant difference in response rates between the schools and the primary care practices. Although schools may

[1] A biased sample in study 4 was also suggested by the finding that, in comparison with the proportion of 'cases' identified elsewhere e.g., Meltzer et al. (2000), a greater proportion of the sample met the study criterion for caseness

support what they perceive to be worthwhile academic endeavours, medical practitioners may reach decisions on the basis of clinical relevance and priority. The clinical context of nursing research and its relevance for the day-to-day activities of practising nurses has been emphasised (Tranmer, Lochhaus-Gerlach & Lam, 2002). Similarly, the relevance of research for primary care practice and the effectiveness of patient care has been emphasised as a determinant of primary care physicians' participation in research (Plane, Beasley, Wiesen, McBride & Underbakke, 1998). Payment to staff for time spent on non-patient care activities is an additional factor (Carey, Kinsinger, Keyserling & Harris, 1996; Plane et al., 1998). In the present studies, conducted as part of a research degree programme, there were no funds for that purpose. Although some practices may be prepared to allow researchers to carry out research activities within the practice and thereby minimise imposition on practice staff, patient confidentiality is likely to remain a consideration.

Recruitment of clinicians by clinicians has also been emphasised as a characteristic of successful practice recruitment (Carey et al., 1996). Specialty matching, however, may be relevant. In the present studies, a respiratory paediatrician and a postgraduate researcher both signed the initial contact letters. Practices in the vicinity of academic institutions are likely to receive numerous requests to participate in research, which may be associated with low recruitment rates (Kelly, McMahon & Hazey, 1992). The present studies were conducted in the vicinity of four Universities.

Favourable attitudes towards medical research have been reported amongst the general public (Madsen, Holm & Riis, 1999) and samples of patients (Madsen et al., 1999; Sugarman, Kass, Goodman, Perentesis, Fernandes & Faden, 1998), with particularly positive attitudes amongst patients who have participated in research (Sugarman et al., 1998). However, patients who participated in research and who received no feedback were likely to have less positive attitudes, and with respect to clinical trials, patient recruitment rates have declined in recent years (Madsen et al., 1999). Factors that may influence patients' decisions about participation in research include the words that are used to describe the research (e.g., clinical trial, medical research) (Sugarman et al., 1998), and the presence of medical research ethics committees (Madsen et al., 1999). However, these findings do not explain the low patient recruitment rate in the present studies. For example, prospective participants were asked to participate in a 'project' and 'study'. These terms are consistent with Sugarman et al.'s (1998) most positive and least threatening descriptor, "Medical Study". Each study had approval from a University or Local Research Ethics Committee. Although it is not known what proportion of the patients received a letter in support of the research from their doctor or practice nurse, it has been suggested that this might only be significant in treatment research (Sugarman et al., 1998). It is suggested that the low response rate may reflect parents' concern about research into the psychological aspects of asthma. That a minority of prospective participants agreed to participate may be explained by altruism i.e., help others and/or advance science, or an interest in psychology. Although, in the present studies, no treatment was offered, the relatively high proportion of parent- and self-reported psychological difficulties may explain why some of the prospective participants were prepared to participate. Participation for any of above reasons would be consistent with patients' reports of the factors that contribute to their decision-making (e.g., Madsen et al., 1999; Sugarman et al., 1998).

Concerning the children's descriptions of what out of breath feels like, it is likely that a child's cognitive ability and verbal mental age are associated with the quality of their description of breathlessness. That these factors were not controlled for is a limitation of the studies reported in chapter 5, chapter 6 and chapter 8. The British Picture Vocabulary Scale (Dunn, Dunn, Whetton & Burley, 1997) may be useful in this respect. The lack of participants from different ethnic groups, of relevance because people from different cultural backgrounds may differ substantially in their beliefs about asthma (Yoos & McMullen, 1996), is a limitation of the studies reported in chapter 7 and chapter 8.

Insofar as the instruments were concerned, there were concerns about the internal reliability of some of the questionnaire sub-scales and their scoring system. A revised IPQ (Moss-Morris, Weinman, Petrie, Horne, Cameron & Buick, 2002) has resolved many of the internal reliability problems associated with the original IPQ, although further modification may be necessary to make the revised instrument suitable for use with children. Beliefs about the child's asthma medication, which may have an influence in more severe groups, where concern about side-effects may be more of an issue, were not assessed. The Beliefs about Medicines Questionnaire (Horne, Weinman & Hankins, 1999) may be particularly useful in this respect.

The thesis of the first two studies was that social interaction, in the context of relevant experience, is a determinant of children's sophisticated descriptions of respiratory sensations. Although generally consistent with the cognitive developmental and functionalist perspectives that were discussed in chapter 1, the findings reported in chapter 5 and chapter 6 suggest that age and experience of asthma together cannot account for the finding that only a proportion of the older children, and the children with asthma provided a detailed description of what out of breath feels like. This was taken as indirect support for the thesis.

It is likely that as children develop they acquire the language of their caregivers to describe their internal states (Mechanic, 1964; Wilkinson, 1988). The early infant states of pain, hunger, loneliness and tiredness (Dunn, 1977) may become a child's primary reference states that determine the language that they use to describe other internal states. The findings of the studies reported in chapter 5 and chapter 6 suggest that tiredness in particular may be a general term that is applied to a variety of internal sensations. Age, experience and social interaction may then facilitate a differentiation of these early internal state terms. The product is suggested to be a set of specific descriptors that may be located within a particular physiological system e.g., 'wheeze', "lungs feel tight". Although some of the terms that children use to describe their internal states are likely to have been constructed from their pre-existing vocabulary e.g., "lungs feel tight", others undoubtedly are acquired through social interaction and the sharing of language e.g., wheeze. This differentiation of early internal state terms and awareness of respiratory sensations is particularly important for childhood asthma sufferers. It allows them to take prompt, appropriate action to minimise or prevent any further exacerbation (Fritz et al., 1996) and may be associated with appropriate treatment decisions.

The self-regulatory model (Leventhal et al., 1984) predicts that perception of symptoms, a potential health threat, motivates patients to reduce their health-related risk, and to act to reduce perceived threat in ways that are consistent with their beliefs about that threat. Analyses reported in chapter 7 and chapter 8 were concerned with the participants' beliefs about asthma. The finding that the children were particularly likely to talk about their symptoms, their triggers and the consequences of their asthma is generally consistent with the thesis that the children's understanding of the different aspects of asthma was determined by the salience of each aspect to their daily lives, and the necessity of acquiring strategies to resolve specific, asthma-related difficulties.

It has been suggested that a single rating of an individual's understanding of disease concepts would be unlikely to represent accurately the variability in their understanding of different aspects of the same disease, or the same aspect of different diseases (Schmidt & Fröhling, 2000). Ideas about symptoms and treatment develop in advance of ideas about cause and prevention (Paterson et al., 1999; Rosenthal et al., 1995; Schmidt & Weishaupt, 1990). This may be due to the functional nature of discourse about illness i.e., its effectiveness in eliciting responses from significant others (Wilkinson, 1988). The ability to perceive accurately and describe respiratory sensations is likely to be advantageous for a young child with asthma. Similarly, the potential triggers of asthma are likely to be salient to a child with asthma who may use that knowledge to minimise their experience of stigma. This has also been suggested as a functional aspect of illness discourse (e.g., Radley, 1994).

In comparison with the other illness representation components, there was greatest concordance in the beliefs of the parents and their child about the Identity (signs and symptoms) of the child's asthma. This is consistent with the finding that people's health behaviour is situated in a context of acute, symptom management e.g., Hunt et al. (1989). Effective disease management requires accurate perception of symptoms (Fritz et al., 1996; Fritz & Wamboldt, 1998).

Perception of symptoms has been associated with distress (Taitel et al., 1998) and psychological disturbance may be a risk for children with severe asthma (Norrish et al., 1977; Wamboldt et al., 1998). In the present studies, the children's parent- and self-reported psychological difficulties were generally not correlated with asthma severity and mean scores were all within the normal range. Other studies have reported similar findings (e.g., Kashani et al., 1988; Nassau & Drotar, 1995; Wamboldt et al., 1998). Although the power of the fourth study may have been too low to detect any significant effect of severity, asthma management may have been effective for the majority of the sample. Effective disease management is likely to be associated with perceptions of disease control. Perceptions of well-controlled asthma have been associated with fewer symptoms, fewer and less serious exacerbations of asthma, less disruption to normal activities and fewer emotional difficulties (Janson & Reed, 2000). In study 4, the mild group parents' perception of the extent to which their child's asthma was controlled was associated with their reports of their child's psychological well-being.

In comparison with the children's self-reports, the parents' reports of their child's psychological difficulties suggested a greater amount of psychological disturbance within the sample. This finding is consistent with reports that the nature and extent of the difficulties that children with asthma may experience vary as a function of the source of information about the child's difficulties

(Kashani et al., 1988; Norrish et al., 1977; Tavormina et al., 1976; Zbikowski & Cohen, 1998), and the suggestion that parent factors may influence parents' reports of their child's psychological well-being (Bender & Klinnert, 1998).

Two theses of the studies reported in chapter 7 and chapter 8 were that concordance in the beliefs of the parents and their child about the child's asthma is associated with less conflict about the child's disease and disease-related situations, and that the quality of family life mediates the relationship between belief concordance and the child's psychological well-being. Several studies have reported associations between illness beliefs and health outcome (e.g., Hampson et al., 1994; Heijmans & De Ridder, 1998). Patients' perceptions of the seriousness of their condition and its consequences, in particular, have been associated with physical functioning, social functioning and mental health (Heijmans, 1999). That illness beliefs may influence patients' behaviour (and their psychological well-being) suggests that it is important to consider the implications of their behaviour in a wider context i.e., the system of beliefs within the patient's family, community and society. The findings of the present studies were consistent with this suggestion: Concordance in the beliefs of the parents and their child about the seriousness of the child's condition were significantly negatively associated with the child's psychological difficulties. Belief concordance has been attributed to shared concerns about asthma that were expressed within a family (Khampalikit, 1983), and in the context of appropriate support provision, shared concern was negatively associated with children's self-reported distress about their asthma and its consequences (Sawyer et al., 2001).

The concerns of childhood asthma sufferers and their parents are likely to be directly related to the way that asthma intrudes upon their lives. Another thesis of the studies reported in chapter 7 and chapter 8 was that the participants' reasons for achieving good control of asthma reflected the aspects of their lives that were most affected by the child's condition. Asthma has been reported to intrude upon patients' physical health, psychological well-being, school attendance, leisure activities, and family life (Action Asthma, 1993; Celano & Geller, 1993; Donnelly et al., 1987; French, Christie & West, 1994; Graetz & Shute, 1995; Hilton, 1991; Hyland, 1998; Hyland et al., 1993; Janson & Reed, 2000; Nocon & Booth, 1991; Osman et al., 1993; Pradel et al., 2001; Snadden & Brown, 1992; Taitel et al., 1998; Wamboldt & Wamboldt, 1996; Yoos & McMullen, 1996). Parents of children with asthma have reported emotional distress as a consequence of their child's asthma, and in particular worry about sudden exacerbations or deterioration, and concern about their child's peer relationships, restriction of family activities, and difficulties in family relationships (Donnelly et al., 1987; Eiser et al., 1992; Paterson & Britten, 2000; Staudenmayer, 1981). Medication has also been reported as an intrusion in patients' lives (Osman et al., 1993). Children have reported concerns about the taste of their inhalers, and the burden of having to take medication regularly (Pradel et al., 2001). Parents have expressed concerns about the side-effects of their child's treatment (Donnelly et al., 1987).

The third and fourth studies have shown that the parents' and the children's reasons for achieving good control of asthma were consistent with these aspects of asthma intrusiveness. Furthermore, although the parents' and the children's reasons for achieving good control of asthma were representative of similar domains in the participants' lives, the organisation of their network of reasons suggested differences in the salience of specific domains. For example, emotional regulation and positive affect were central in the motivation system of the participants. However, recreation e.g., being able to participate in physical activities without disruption because of asthma was also central in the motivation system of the children, whereas general quality of life was also central in the motivation system of the parents.

These differences can be explained in terms of cognitive development and the salience of different aspects of asthma intrusiveness. For example, the finding that, in comparison with the children, the parents were more likely to represent the Quality of Life domain suggested a developmental difference in conceptualisation. Although many of the children talked about reasons for achieving good control of asthma that were representative of the Quality of Life domain, 'Quality of Life' was less central in their motivation system i.e., was less integrated with other domains. Emotional well-being and freedom from restriction of activity were the central domains in the motivation system of the children and suggested the children's primary concern with the specific and personally salient, potential consequences of their condition. The centrality of the Quality of Life and Affect domains in the parents' motivation system suggested a similar concern with personally salient, potential consequences i.e., their child's emotional well-being, that exists in parallel with their concern about more general and abstract potential consequences.

As with the previous analyses, the findings concerning the participants' reasons for achieving good control of asthma were consistent with Leventhal et al.'s (1984) self-regulatory model. For example, a child's representation of a health threat (symptoms during exercise) that is a barrier to their goal (participate in sports) may lead to a coping plan (use relief inhaler before exercise). The child's cognitive representation of the Exacerbation (symptoms might triggered by exercise) and Cure/Control (exercise-induced symptoms can be controlled by the use of relief inhaler before exercise) components of illness representation thus enable the child to develop a coping plan to achieve their goal.

The limitations and findings of the present studies suggest areas for future research. In particular, it would be useful to know how concordance in the beliefs of parents and their child about asthma may be associated with the child's psychological well-being. Assessment of family functioning in the context of the child's condition may provide some useful answers. It may also be useful to improve our knowledge about the determinants of belief concordance, in particular clarification of the content and significance of family discussion about asthma. Research involving an objective measure of asthma severity and a sufficient number of participants to test for associations between asthma severity and beliefs about asthma, and between asthma severity and psychological well-being would make a significant contribution to the literature.

Differences in the organisation of the participants' motivation system may inform cognitive-behavioural interventions to encourage adherence with treatment recommendations. However, it should be noted that the procedure in study 3 and study 4 asked about the participants' reasons for achieving good control of asthma. Attitudinal research in psychology e.g., Ajzen (1988), Fishbein and Ajzen (1980), has advocated behavioural specificity to optimise the predictive utility of cognitive variables. To inform interventions that are likely to be effective in primary care settings and that are consistent with recent developments in motivational interviewing e.g., Emmons and Rollnick (2001), Stott, Rollnick, Rees and Pill (1995), future research should enquire about patients' reasons for using/not using inhalers.

The development of an effective outcome measure for asthma care remains a priority (Moss et al., 1996). The qualitative data on reasons for achieving good control of asthma may be useful in this respect.

In conclusion, it is suggested that the personal salience of different aspects of childhood asthma is a thread that runs throughout the studies. It may encourage an awareness of symptoms, prompt discussion of internal states, foster concordance in beliefs and motivate adherence with treatment recommendations. Each of these factors has been linked with a good outcome for children with asthma.

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Appendix

Beliefs about asthma short questionnaire (demographic and clinical information)

Modified asthma-specific Illness Perception Questionnaire (parent-version)

Modified asthma-specific Illness Perception Questionnaire (child-version)

Strengths and Difficulties Questionnaire (P4-16) (extended version)

Strengths and Difficulties Questionnaire (S11-16) (extended version)

Beliefs about Asthma Short Questionnaire

Thank you for allowing us to speak with you and your child. Please would be kind enough to answer the following questions as it will provide background information which will help us to improve our understanding of asthma.

1. Please state your occupation and the occupation of your spouse/partner:
   ....
   ....

2. (a) What is your child's date of birth? ....

   (b) How old is your child? ....

3. Are you currently living with a spouse or partner? (please circle as appropriate)

   Yes No

4. In total, how many children live in your household? ....

5. Other than your child, does anyone in your household have a history of asthma?

   (please circle as appropriate)

   Yes No

   If yes, please state who in your household has a history of asthma (for example, spouse, partner, eldest son, middle son, youngest daughter, youngest stepson, oldest stepdaughter).
   ....

6. Does anyone in your household smoke?

   (please circle as appropriate)

   Yes No

   If yes, how many people in your household smoke?

   ....

7. (a) How old was your child when your child was first diagnosed as having asthma?
   ....

   (b) How long before your child was first diagnosed as having asthma were you aware that your child was having problems of that nature?
   ....

   (c) Before your child was diagnosed as having asthma, was there anything in particular that first made you think your child was having problems of that nature?
   ....
   ....
   ....
   ....

   (d) Please give details of any medication your child is on by completing the form overleaf:

Medication details

Name .... Participant No. ....

Drug	Type of inhaler
Reliever	**Puffer**
Bronchodilators Salbutamol, Ventolin, Bricanyl, Terbutaline, Atrovent, (there are a few others which are rarely prescribed)	Metered dose inhaler
	Breath activated
	Turbohaler Diskhaler Accuhaler Clickhaler Autohaler Easi-breathe Rotahaler Spinhaler
Preventer	
Inhaled steroid (Becotide & Becloforte series, Beclazone series, Pulmicort, Flixotide)	
Others Cromoglycate (Intal) Nedrocromil (Tilade)	
Theophyllines Uniphylline, Slophylline, Nuelin, Aminophylline, Theodur (NB there are different strengths for each of these)	
Leukotriene receptor antagonists (Singulair; Accolate)	
Emergency treatment Oral steroids (Prednisolone, Prednisone)	

Drug

Type of inhaler

Dose per puff/tablet

Number of puffs/dose per day usually used

Drug

Type of inhaler

Dose per puff/tablet

Number of puffs/dose per day usually used

Drug

Type of inhaler

Dose per puff/tablet

Number of puffs/dose per day usually used

Drug

Type of inhaler

Dose per puff/tablet

Number of puffs/dose per day usually used

Drug

Type of inhaler

Dose per puff/tablet

Number of puffs/dose per day usually used

Beliefs about Asthma Short Questionnaire

(continued)

(e) How long is it since your child last had an asthma attack?

....

(f) Please indicate on the scale below how well controlled your child's asthma is:

(please tick as appropriate)

very poorly controlled ❑ ❑ ❑ ❑ ❑ ❑ ❑ very well controlled

You have now completed the questionnaire. Thank you.

YOUR VIEWS ABOUT YOUR CHILD'S ASTHMA

Listed below are a number of symptoms that your child may or may not have experienced as part of their asthma. Please indicate whether your child has experienced any of these symptoms by ticking the appropriate box.

SYMPTOM	ALL THE TIME	FREQUENTLY	OCCASIONALLY	NEVER
Pain				
Nausea				
Breathlessness				
Weight gain				
Fatigue				
Tight chest				
Cough				
Panic attacks				
Headaches				
Upset stomach				
Sleep difficulties				
Nervous tension				
Weight loss				
Spots				
Sore eyes				
Toothache				
Anxiety				
Sore throat				
Wheezing				
Hair falling out				
Dizziness				
Feeling shaky				
Loss of strength				

We are interested in your own personal views of how you now see your child's asthma. Please indicate how much you agree or disagree with the following statements about your child's asthma by ticking the appropriate box.

	VIEWS ABOUT YOUR CHILD'S ASTHMA	STRONGLY AGREE	AGREE	NEITHER AGREE NOR DISAGREE	DISAGREE	STRONGLY DISAGREE
[illegible]	A germ or virus caused my child's asthma to begin with					
[illegible]	Diet played a major role in causing my child's asthma to begin with					
[illegible]	My child's diet can make their asthma worse					
[illegible]	Colds can make my child's asthma worse					
[illegible]	Pollution of the environment caused my child's asthma in the first place					
[illegible]	Pollution of the environment can make my child's asthma worse					
[illegible]	My child's asthma is heredity - it runs in our family					

YOUR VIEWS ABOUT YOUR CHILD'S ASTHMA
(Continued)

	VIEWS ABOUT YOUR CHILD'S ASTHMA	STRONGLY AGREE	AGREE	NEITHER AGREE NOR DISAGREE	DISAGREE	STRONGLY DISAGREE
IP5	It was just by chance that my child got asthma					
IPE3	It is just by chance if my child's asthma gets worse					
IP6	Stress was a major factor in causing my child's asthma in the first place					
IPE4	Stress can make my child's asthma worse					
IPC	Being near cats or dogs or other animals can make my child's asthma worse					
IPC	Cigarette smoke can make my child's asthma worse					
IP7	My child's asthma is largely due to my child's behaviour					
IPE5	If my child's asthma gets worse it is largely due to my child's behaviour					
IPA1	It's my fault that my child has asthma					
IPE6	If my child's asthma gets worse it is my fault					
IP8	Other people played a large role in causing my child's asthma					
IPE7	If my child's asthma gets worse it is other people's fault					
IP9	My child's asthma was caused by poor medical care in the past					
IPE2	If my child's asthma gets worse it is the doctor's and nurse's fault					
IPA2	No-one is to blame for my child having asthma					
IPE1	It's no-one's fault if my child's asthma gets worse					
PCA1	My child's state of mind can make their asthma worse					
IPCA2	My child's state of mind can make their asthma better					
IP10	My child's state of mind played a major part in causing their asthma					
IP11	My child will have asthma for only a short time					
IP12	My child's asthma is likely to be permanent rather than temporary					
IP13	My child will have asthma for a long time					
IPT1	My child will always have asthma					
IP14	My child's asthma is a serious condition					
IP14a	Having a child with asthma is having a child with a serious medical condition					

YOUR VIEWS ABOUT YOUR CHILD'S ASTHMA
(Continued)

	VIEWS ABOUT YOUR CHILD'S ASTHMA	STRONGLY AGREE	AGREE	NEITHER AGREE NOR DISAGREE	DISAGREE	STRONGLY DISAGREE
IP15	My child's asthma has had major consequences on their life					
IP16	My child's asthma has become easier for my child to live with					
IP17	My child's asthma has not had much effect on their life					
IP18	My child's asthma has strongly affected the way others see my child					
IP19	My child's asthma has serious economic and financial consequences					
IP20	My child's asthma has strongly affected the way my child sees himself/herself as a person					
IP21	My child's asthma will improve in time					
IP22	There is a lot that my child can do to control their symptoms					
IP23	There is very little that can be done to improve my child's asthma					
IP24	My child's treatment is effective in controlling their asthma					
IPCu1	My child's treatment will be effective in curing their asthma					
IP25	My child's recovery from their asthma is largely dependent on chance or fate					
IP26	What my child does can determine whether their asthma gets better or worse					

YOUR VIEWS ABOUT YOUR ASTHMA

Here are a few things (symptoms) that you may or may not have experienced as part of your asthma. Please read through these and tick a box to let us know if you have experienced any of them.

SYMPTOM	ALL THE TIME	FREQUENTLY	OCCASIONALLY	NEVER
Pain				
Feeling sick				
Feeling out of breath				
Putting on weight				
Feeling tired				
Tight chest				
Cough				
Suddenly feeling scared/panicky				
Head-aches				
Upset tummy				
Hard to sleep				
Feeling nervous or stressed out/find it hard to relax				
Losing weight				
Spots				
Sore eyes				
Toothache				
Feeling worried when you think about your asthma				
Sore throat				
Wheezing				
Hair falling out				
Feeling dizzy				
Feeling shakey				
Feeling weak				

Here are a few things that some people believe about asthma. Please read these through and tick a box to let us know how much you agree with each of them.

	VIEWS ABOUT YOUR ASTHMA	STRONGLY AGREE	AGREE	NEITHER AGREE NOR DISAGREE	DISAGREE	STRONGLY DISAGREE
P1	A germ or virus caused my asthma to begin with					
[illegible]	Things I ate and drank helped cause my asthma to begin with					
[illegible]	Things I eat and drink can make my asthma worse					
[illegible]	Colds can make my asthma worse					
[illegible]	Dirty air helped cause my asthma in the first place					

YOUR VIEWS ABOUT YOUR ASTHMA
(Continued)

	VIEWS ABOUT YOUR ASTHMA	STRONGLY AGREE	AGREE	NEITHER AGREE NOR DISAGREE	DISAGREE	STRONGLY DISAGREE
IPE2	Dirty air can make my asthma worse					
IP4	Asthma is something that runs in my family					
IP5	It was just bad luck that I have asthma					
IPE3	Bad luck can make my asthma worse					
IP6	Stress helped cause my asthma in the first place					
IPE4	Stress can make my asthma worse					
IPC	Being near cats or dogs or other animals can make my asthma worse					
IPC	Cigarette smoke can make my asthma worse					
IP7	It's my fault that I have asthma					
IPE5	If my asthma gets worse it is my own fault					
IP8	It's other people's fault that I have asthma					
IPE7	If my asthma gets worse it is other people's fault					
IP9	Doctors and nurses helped cause my asthma					
IPE6	If my asthma gets worse it is the doctor's and nurse's fault					
IPA2	It's no-one's fault that I have asthma					
IPE8	It's no-one's fault if my asthma gets worse					
PCA1	How I think and feel can make my asthma worse					
IPCA2	How I think and feel can make my asthma better					
IP10	How I think and feel caused my asthma in the first place					
IP11	I won't have asthma when I'm a bit older					
IP12	When I'm grown-up I won't have asthma					
IP13	When I'm old I won't have asthma					
IPT1	I will always have asthma					
IP14	My asthma is a serious illness					
IP14i	Having asthma is having a serious illness					
IP15	My asthma has had big effects on things I can do					

YOUR VIEWS ABOUT YOUR ASTHMA
(Continued)

	VIEWS ABOUT YOUR ASTHMA	STRONGLY AGREE	AGREE	NEITHER AGREE NOR DISAGREE	DISAGREE	STRONGLY DISAGREE
IP16	It isn't that bad having asthma					
IP17	My asthma has not had much effect on things I can do					
IP18	People think I'm different because I have asthma					
IP20a	My asthma has had a big effect on how I think about myself					
IP20b	My asthma has had a big effect on how I feel about myself					
IP20c	I think I am different to other people because I have asthma					
IP21	My asthma will eventually get better					
IP22	There is a lot that I can do to make my asthma better					
IP23	Nothing much can help make my asthma better					
IP24	My asthma medicine makes my asthma better					
IPCu1	My asthma medicine will cure my asthma					
IP25	It will just be good luck if I ever get better					
IP26	Things I do can make my asthma better or worse					

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— END